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UNIVERSITY OF SAN DIEGO
Hahn School of Nursing and Health Science
DOCTOR OF PHILOSOPHY OF NURSING

HOPE, UNCERTAINTY, AND COPING AMONG
PARENTS OF CHILDREN WITH CANCER

By

Christine Ann Sloan

A dissertation presented to the
FACULTY OF THE HAHN SCHOOL OF NURSING AND HEALTH SCIENCE
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requirements of the degree
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Dissertation Committee
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This study found that parental hope is influenced by uncertainty; as uncertainty decreases, hope increases. Increased parental age is associated with decreased hope and coping. As days from diagnosis increase, uncertainty increases. Single parents have higher levels of uncertainty than parents who are in a committed relationship as do parents who have less than a 12th grade education. Surprisingly, multivariate regression did not support the influence of hope or uncertainty on coping outcomes as suggested by Mishel's framework. Parent groups at risk for psychosocial problems are identified and evidence is provided to support the need for intensive and ongoing psychosocial support for parents of children with cancer.

Dedication

This dissertation is dedicated to each of the families represented in this study who graciously shared their thoughts, their stories and their time! Thank you for being willing to serve others through your participation in this study.

I especially dedicate this to Jennilie Floresvillar. May you rest in peace and may your family be comforted by the hope that others will benefit from what was learned in your case.

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Chapter 1

Introduction

Childhood cancer is a rare and unexpected event. Upon diagnosis, normal day to day life stops and is replaced by a “rollercoaster ride” of tests, treatments, and decisions (Fletcher, Schneider, & Harry, 2010). The need for immediate intervention plunges the child and the family into a new world of treatments and tests in an unfamiliar environment. Making decisions they feel are “right” for them and their child while facing a barrage of unfamiliar medical terms, routines, and treatments is frightening (Madeo, O’Brien, Bernhardt, & Biesecker, 2012). Parents are often in shock, unable to comprehend the implications of the diagnosis. Most families simply want reassurance that their child will survive. However, surety is not an option. Most healthcare providers seek to provide accurate information while delivering as much hope as possible (Salmon et al., 2012). Even with a favorable diagnosis the future is uncertain and guarantees for survival cannot be made (Roberta Lynn Woodgate & Degner, 2002). Gaining a clearer picture of the relationship between hope, uncertainty, and coping in parents may allow healthcare providers further insight into factors that influence caregiver behaviors while caring for their child with cancer thus enhancing opportunities to improve care.

Background

Unintentional accidents are the leading cause of death in children ages 5-14 years old. However when considering death due to disease, cancer is the leading cause of death

in children ages 5 to 19 years old in the United States. In 2014, in children between the ages of birth and 19 years of age, approximately 10,450 were diagnosed with a malignancy and 1350 deaths occurred (Ward, DeSantis, Robbins, Kohler, & Jemal, 2014). In this same year, an additional 5330 cases were anticipated among adolescents (ages 14 – 19) with 610 deaths occurring. Among adults 1,665,540 new cases of cancer were expected in 2014; 585,720 deaths were anticipated (approximately 35% mortality)(Siegel, Ma, Zou, & Jemal, 2014). In comparison to adult cancers, pediatric cancers are exceeding rare and children have a much better survival rate.

Fifty years ago a pediatric cancer diagnosis was virtually a death sentence; however clinical research and evolving medical treatments have changed this outlook. Advances in medicine and public health have drastically reduced overall child mortality in the United States over the last 100 years (Field & Behrman, 2003). Success in treating pediatric cancer is no exception as overall survival rates now approach 80-85 percent (Landier, Leonard, & Ruccione, 2013). However, improved pediatric cancer survival rates may be accompanied by false hopes of averting death for both parents and healthcare providers (Field & Behrman, 2003). The natural tendency of healthcare providers is to focus their medical efforts on the high success rate of cancer treatment and the strong hope for a cure. Healthcare providers must be intentional in seeking out and developing appropriate, timely, and compassionate care for parents and families that preserves hope yet assists the family in coping with the diagnosis as no guarantee of survival can be made (Steinhauser, Christakis, Clipp, & McIntyre, 2000).

Significance of the Problem

Knowledge that a child has a life-threatening or life-limiting disease radically changes family dynamics and family function. Bjork, Wiebe, and Hallstrom (2005) found parents experienced “a broken life world” (p.269) and were “striving to survive” (p.270). These themes were identified by parents who felt they had lost their sense of security, become dependent on others, and experienced a change in their daily home life. Families ‘striving to survive’ looked for hope and sought a positive focus to upon which to reorient their lives.

Both in the hospital and at home, parents often take on the job of full-time caregiver. Everyday family life requires adaptation to new routines; medication administration, protection from infection, doctor’s appointments, and tests (Flury, Caflisch, Ullmann-Bremi, & Spichiger, 2011). Some research suggests parents take on a high level of extraordinary parenting characterized by nurturing, disciplining, and monitoring of their home-life when caring for a child with cancer (Anderson, Riesch, Pridham, Lutz, & Becker, 2010). Parents found being intentional in parenting required work while dealing with an uncertain future.

The diagnosis of cancer marks the beginning of an unknown journey. All family members are affected by the diagnosis and struggle to deal with the day to day treatments while operating under a cloud of looming uncertainty. While survival rates have improved, there is no guarantee that death can be averted (Björk, Wiebe, & Hallström, 2005). Parents must balance the needs of the sick child while maintaining other life responsibilities such as a job, raising a family, and caring for their own parents or elders.

Although pediatric cancer is exceedingly rare compared to adult cancer cases, it is a life-altering event for those children and families who are diagnosed (Siegel et al., 2014) and dying from cancer (Ward et al., 2014).

Both nurses and physicians play a key role in helping families to navigate the realities of a childhood cancer diagnosis. As round the clock caregivers at the bedside, nurses often walk with families through the entire disease trajectory from diagnosis to death. Caring for pediatric oncology patients and their families day in and day out although rewarding can be extremely stressful (Beckstrand, Rawle, Callister, & Mandleco, 2009). Families rely on nurses to provide information and interpret medical jargon that can be confusing and frustrating. How nurses respond to questions and inquiries directly affects parent's perceptions and their understanding of the healthcare being given (Chris Feudtner, 2007; Roscigno et al., 2012). An understanding of the relationships hope, uncertainty and coping may provide important information for the development of supportive interventions for families experiencing childhood cancer.

Study Concepts

Uncertainty

Uncertainty is the hallmark of cancer, characterized by a lack of knowing the outcome and the presence of doubt. Uncertain is an adjective defined as “not exactly known or decided; not sure; having some doubt” (Uncertainty, n.d.). Mishel (1981) defines uncertainty as the inability to ascribe meaning to particular events or being unable to determine outcomes. Uncertainty is determined by both the stimulus (the event or information) and the receiver's perception or an interaction between the two (Mishel,

1983). This uncertainty manifests itself in parents at all points along the cancer continuum and persists even after the child has been declared cured (Hovén, Anclair, Samuelsson, Kogner, & Boman, 2008).

Pervasive uncertainty directly influences parental decision-making. Parents bear the burden of making decisions that affect their child's well-being (Stewart, Pyke-Grimm, & Kelly, 2012). Parents want to make *the right decision*. Uncertainty makes the decision more difficult and has significant emotional consequences. Parents look to providers to provide signs or markers that *the right decision* has been made. Mack et al (2006) determined parents often do not receive the level of prognostic information desired, which speaks to a tendency on the part of providers to withhold upsetting information despite the parents desire for truthfulness.

Uncertainty appears to be most pronounced when the child's disease has relapsed (K. K. Boman, Viksten, Kogner, & Samuelsson, 2004; K. Boman, Lindahl, & Bjork, 2003; Clarke-Steffen, 1993; Hoven, Anclair, Samuelsson, Kogner, & Bowman, 2008; Santacroce, 2001). After a period of remission, uncertainty is most acute as parents have had the fear of relapse confirmed and the concomitant poor prognosis established (De Graves & Aranda, 2008; Lin, Yeh, & Mishel, 2010). Even at end of life, uncertainty about impending death tends to hinder parents in letting go. It allows the possibility of cure to linger until the very last breath (M C Kars, Grypdonck, Beishuizen, Meijer-van den Bergh, & van Delden, 2010; Reder & Serwint, 2009).

Coping

Ideally, coping is a positive and dynamic process that should ultimately assist parents in managing the stressors associated with their child's cancer diagnosis and activate measures to deal with the ongoing nature of treatment. Individuals vary their coping strategies based on their individual situational appraisal of the event and their actual or perceived control over the stressful events surrounding the illness. Cancer presents a condition of uncontrollability. Parents have no choice but to cope with the diagnosis. Folkman et al. (1986) defined coping as "cognitive and behavioral efforts to manage specific internal and or external demands that are perceived as taxing or exceeding a person's resources" (p.993). Important to this definition is the view that coping behavior is neutral and can be expressed positively or negatively. Appraisal of the circumstances evokes emotions which are positive or negative. These emotions often drive the coping mechanisms employed (Last & Grootenhuis, 1998). Problem-focused coping often seeks to manage the problem causing stress (external focus) versus emotion-focused coping which seeks to regulate the effects of the environment on the person (internal focus) (Folkman, Dunkel-Schetter, DeLongis, & Gruen, 1985). The drivers of coping are multifactorial.

Considerable strain is placed on families when a cancer diagnosis occurs in their child. Parents have reflected their child's cancer diagnosis was the most overwhelming experience they had ever had and resulted in long-lasting negative changes in their life (Van Dongen-Melman, Van Zuuren, & Verhulst, 1998). These changes were experienced as a series of losses of a safe world-view, a stable marriage relationship, and

loss of the child's normal function or potential due to long term effects of the disease (including death). These same researchers also found parents suffered constant perseveration of uncertainty and anxiety related to the diagnosis. Svavarsdottir (2005) found within the first 20 months of diagnosis, the greatest stressor is caring for the child who is ill, as well as meeting the needs of the rest of the family. These conditions implore a coping response.

Unfortunately, the effects of the stress of dealing with a child's cancer are multifactorial and long-lasting. In a study of parents whose children were diagnosed between 4 weeks and 14 years from the time of evaluation revealed most disease-related stressors (loss of control, self-esteem, sleep disturbances) decreased over time (K. Boman et al., 2003). However, in this same group uncertainty, disease related fear, and loneliness persisted despite the increasing time since diagnosis. Enduring negative effects continue long after the initial shock of the diagnosis.

Hope is thought to be an important contributor to coping (Folkman et al., 1986). According to several authors (Farran, Herth, & Popovich, 1995; Folkman et al., 1986; Lazarus, 1999; M. Mishel, 1988) the appraisal of an event, determines the type of coping strategy employed. Hope is one of the possible outcomes of that appraisal. Hope can be energizing and bring fresh perspective to a bleak situation (Lazarus, 1999). Snyder et al. (1991b) postulated that hope is characterized by a sense of agency (goal-directed determination) and pathways (planning a way to meet a goal). Dufault and Martocchio (1985) characterized the spheres of hope, one of which is an affective dimension that offers the possibility of hope as a motivator for action. In this sphere, hope (or the loss of

it) can be both positive and negative. Hope influences coping both positively and negatively.

Hope

Hope is often described as a cognitive process requiring recognition of a threat and processes to avert that threat (Mednick et al., 2007; C R Snyder, 2000; C R Snyder et al., 1991a), a feeling or emotion that must be managed (Lazarus, 1999; Tong, Fredrickson, Chang, & Lim, 2010; Truitt, Biesecker, Capone, Bailey, & Erby, 2012) and a way of behaving or relating to achieve goals (Fitzgerald Miller, 2007; C R Snyder et al., 1991a; M. G. Wong & Heriot, 2008). Hope has also been described as a state (feelings about a particular situation) and as a trait (an approach to life) (C R Snyder, 2000). Dufault and Martocchio (1985) describe hope as “a multidimensional life force characterized by a confident yet uncertain expectation of achieving a future good which to the hoping person is realistically possible and personally significant” (p.380).

Feudtner (2005) postulates that robust hope, carefully tended can mobilize us to positive action while ineffectual or false hope can be harmful. Several different concepts of parental hope have been hypothesized and will be further explored in the literature review.

Purpose

The purpose of this study is to examine the relationships between levels of hope, uncertainty, and coping among parents of children being treated for pediatric cancer at a large tertiary pediatric cancer center in the southwest United States. Specific research questions of the study include the following: 1) What are the socioeconomic and

demographic characteristics that define this parent population? 2) What are the demographic and disease characteristics of the child undergoing treatment for cancer? 3) What is the relationship between levels of hope, uncertainty, coping and selected demographic variables? These questions will be answered by appraising specific aims.

Specific Aims:

- Aim 1. Describe a sample of parent/child dyads of children with cancer receiving services at a large, academic pediatric healthcare center in southern California.
- Aim 2. Examine the relationships between hope, uncertainty, and coping among a sample of parents with cancer receiving services at a large, academic pediatric healthcare center in southern California.
- Aim 3. Examine the influence of days since cancer diagnosis, parent relationship status, parent relationship to child, parent education, child disease status, hope, and uncertainty on coping.

Conceptual Framework

The concepts of hope, uncertainty, and coping, while loosely defined are tightly interwoven and difficult to tease apart in the context of a family dealing with a pediatric cancer diagnosis. The use of a conceptual model is very helpful in providing a lens through which to guide the inquiry and interpret gathered information (D.F. Polit & Beck, 2012). Figure 1 illustrates the Model of Perceived Uncertainty in Illness, (Mishel, 1983) the conceptual framework used in this study. This framework postulates that uncertainty transpires from an inability to create meaning as it relates to the illness. Families are unable to assign value to illness-related events thus interfering with an accurate appraisal of the significance and consequences of the illness. According to the model, uncertainty presents itself in several forms; 1) ambiguity, 2) lack of clarity, 3) lack of information and, 4) unpredictability (Mishel, 1983).

The primary antecedent for uncertainty is referred to as the “stimuli frame”. The stimuli consist of symptom pattern, event familiarity and event congruence (the consistency between expected and actual illness-related events). These stimuli are processed by parents based on cognitive capacity and the structure providers available. The structure providers identified in this model are a) credible authority (healthcare providers) b) social support, and c) educational level of the parent. The event is then either appraised as an opportunity or a danger. The appraisal then drives the mechanisms used to cope with uncertainty. A negative or danger appraisal leads to the use of mobilizing (direct action, vigilance, and information-seeking) and affect-control strategies (faith, disengagement, and cognitive support). A positive or opportunity

appraisal leads to the use of buffering strategies as a coping mechanism. Buffering strategies are used to block input that can transform uncertainty into a danger. These mechanisms are described as avoidance, selective ignoring, reordering of priorities, and neutralizing (Mishel, 1988).

The framework, derived from the empirical literature, provides a context for the key variables under study which are hope, uncertainty, and coping. Demographic information for the parent and their child as well as disease characteristics of the child will also be collected to enhance understanding. An investigation of the relationship between hope, uncertainty, and coping requires gaining a perspective of the intimate interconnectedness of these three constructs (Clayton, Butow, Arnold, & Tattersall, 2005; Folkman, 2010; M. Mishel, 1988). Mishel's model is unique in that although uncertainty is often viewed as a threat, it leaves open the possibility for personal transformation and a positive outcome (Mishel, 1988; Mishel, 1983).

Chapter 2

Literature Review

This chapter will provide an extensive review of the literature related to relevant research on hope, uncertainty, and coping and their implications for parenting a child being treated for cancer. The concepts of hope, uncertainty, and coping will be explored and defined through various theories and perspectives. The state of the science on these constructs will be reviewed and integrated to provide a background for further description of the research problem. Lastly, a conceptual framework will be introduced to examine study variables.

A search of nursing, medical, and allied health literature was conducted by accessing the electronic library systems the University of San Diego and the University of California, San Diego. The search was initiated using the Cumulative Index to Nursing & Allied Health Literature (CINAHL) database, PsycINFO, Google Scholar, and the National Library of Medicine Pub Med databases. Key words searched included cancer, child, parent, death, hope, uncertainty, and coping. The search was limited to publications between 1981 and the present. Public websites for the National Cancer Institute, the American Children's Cancer Organization, and the Children's Oncology Group were also accessed to obtain information and statistics regarding pediatric cancer in the United States.

An understanding of the relationship between hope, uncertainty, and coping requires gaining a perspective of the intimate interconnectedness of these three constructs (Clayton et al., 2005; Folkman, 2010; M. Mishel, 1988). These concepts while loosely defined are tightly interwoven in relationship to each other and difficult to tease apart. Close examination of each concept will attempt to provide a base upon which to appreciate the many connections between these concepts. Extant research regarding hope, uncertainty, and coping will also be reviewed and analyzed, gaps identified, and significance to nursing explored.

Hope

Hope is the thing with feathers
That perches in the soul,
And sings the tune without the words,
And never stops at all,

And sweetest in the gale is heard;
And sore must be the storm
That could abash the little bird
That kept so many warm.

I've heard it in the chillest land,
And on the strangest sea;
Yet, never, in extremity,
It asked a crumb of me.

Emily Dickinson

Many have tried to define hope, however by its abstract and highly personal nature the definition remains open to interpretation. Throughout history, hope has been and continues to be portrayed as a critical life force. References to hope are present in nearly every form of literature, ancient to modern day. There are hundreds of references to hope in all of the major religious texts of the world (the Bible, the Torah, and the Koran). It is used in every day vernacular; both casually, "I hope we can go on vacation", and in times of desperation "I hope she lives." We take its presence for granted

and are devastated when it's dashed (Farran et al., 1995). Definitions from psychology, medicine, and religion, as well as proposed theories of hope will be explored to provide a broad conceptualization of hope.

Definitions and descriptions of hope

Hope as defined by the dictionary is a “feeling of expectation and a desire for a certain thing to happen” when used as a noun. As a verb, hope implies “wanting something to happen or be the case” (Hope, n.d.). As an adjective, *hopeful*, there is less of an object of hope and more of an expression of generalized hope, “I am hopeful even though the treatment didn't work” (Farran et al., 1995). The context in which hope is described affects the definition. Most of the medical or psychology literature explores hope in the context of disability or life-threatening illness.

Hope is often described as a cognitive process requiring recognition of a threat and processes to avert that threat (Mednick et al., 2007; C R Snyder, 2000; Snyder et al., 1991), a feeling or emotion that must be managed (Lazarus, 1999; Tong et al., 2010; Truitt et al., 2012), and a way of behaving or relating to achieve goals (Fitzgerald Miller, 2007; Snyder et al., 1991; Wong & Heriot, 2008). Hope has also been described as a state (feelings about a particular situation) and as a trait (an approach to life) (Snyder, 2000). One of the most inclusive definitions of hope incorporates many of these characteristics:

Hope constitutes an essential experience of the human condition. It functions as a way of feeling, a way of thinking and a way of behaving, and a way of relating to one's self and one's world. Hope has the ability to be fluid in its expectations, and in the event that the desired object or

outcome does not occur, hope can still be present (Farran et al., 1995, p. 6).

Herth (1993) undertook a study to describe hope from the viewpoint of family caregivers caring for a loved one who was terminally ill. Using triangulation, Herth collected data over time both by interview and self-report. Her findings of hope fostering strategies, as well as hope hindering strategies were used to describe hope in this population as both multidimensional and dynamic. Hope was defined as “a dynamic inner power that enables transcendence of the present situation and fosters a positive new awareness of being” (Herth, 1993, p. 544).

Lazarus, from a perspective of modified subjectivism (1999) posits that hope is more than a desire (emotion) it has a cognitive component that requires a belief in the possibility of a favorable outcome. It serves as a resource to help us cope in times of difficulty or uncertainty. Lazarus suggests three themes from which his concept of hope is derived 1) each person brings a distinct perspective to his or her appraisal of what is occurring and about the wellbeing of ourselves and others, 2) coping is the strategy we choose to “think, feel, and act to advance our cause” based on our appraisal of conditions affecting us, and 3) the meaning we construct from our circumstances is a product of environment and personality (Lazarus, 1999, p 658).

Hope can be described in terms of its relationship to other conditions and outcomes. Folkman (2010) in her essay on hope in the context of stress and coping theory suggests that hope is a cognitive state with emotional tones that helps us manage uncertainty while coping with a changing reality. Hope serves to offset the sources of anxiety that threaten to destabilize our sense of safety during periods of uncertainty. The

dynamic nature of hope allows us to manage uncertainty by holding onto contradictory propositions concurrently. This ability to hold onto hope in the face of significant adversity is characteristic of the parents of children suffering from cancer and other life-threatening illnesses (Barrera et al., 2013; Granek et al., 2013; Horton & Wallander, 2001; Kauser, Jevne, & Sobsey, 2003; Samson et al., 2009).

Jerome Groopman, an adult oncologist and author, writes from his clinical experience with cancer patients treated in the early 1980's when cure was rare and death a frequent occurrence. Groopman questioned how some patients could sustain hope during difficult circumstances and other could not. He defines hope as "the elevated feeling we experience when we see – in the mind's eye – a path to a better future. Hope acknowledges the significant obstacles and deep pitfalls along that path. True hope has no room for delusions" (Groopman, 2004, p xiv). Groopman is clear to point out that hope is not the same as optimism. Hope is not 'positive thinking', it's based upon a clear understanding of the situation at hand and serves as an anchor from which to temper fear and endure difficulties (Groopman, 2004).

A definition of hope is elusive as it can manifest in a number of ways. Those trying to define hope more often note that hope is often defined by what it is not. Miceli and Castelfranchi (2010) in their essay on hope, discuss the challenge of providing a clear definition of hope. Hope is perplexing because of the sheer difficulty distinguishing it as different or at least somewhat distinct from other "anticipatory representations"(p.254). Anticipatory representations are defined by these authors as 'expectancies' or outcomes of a particular kind of thinking. They argue hope is not the same as faith, optimism or trust. These three anticipatory representations inherently imply positive expectation or a

commitment to a positive outcome. Trust implies commitment to and confidence about the fulfillment of the desired thing. Hope does not require positive expectation or an assumed commitment. One can still hope while harboring a negative expectation. Faith is similar to trust but differs in that it implies a confidence or certainty of the outcome and can be held independent of the evidence. Hope is actually more present when there is more uncertainty about outcome (Miceli & Castelfranchi, 2010). Based on these assertions, hope is not the same as trust, optimism, or faith.

While difficult to define, hope has some transcendent qualities that allow an individual to cope with adversity. Many studies have shown that hope is essential to coping for parents whose child has a life-threatening illness (Bayat, Erdem, & Gul Kuzucu, 2008; De Graves & Aranda, 2008; Granek et al., 2013; Nikolaichuck, Jevne, & Maguire, 1999; Reder & Serwint, 2009). Hope can be both a resource and when absent, a liability (Amador, Reichart, Lima, & Collet, 2013; Bayat et al., 2008; Morse & Penrod, 1999). Hope is described as both tenacious and tenuous depending upon one's appraisal of the clinical situation (Barrera et al., 2013). Hope involves both affective and cognitive processes (Lazarus, 1999; Salmon et al., 2012; Tong et al., 2010). While a clear and comprehensive definition of hope does not exist, its importance and impact on healthcare warrants additional study.

Theories of hope

Several theories of hope have been proposed throughout the psychology and nursing literature. While many theories have been suggested, there is no one specific theory that is relied upon consistently. As defined by Dufault and Martoccio (1985), hope is highly contextual. A particular theory may be more useful in a specific patient

population or scenario. One of the most frequent contexts of hope is the condition of loss (e.g. physical, personal, financial, possessions). For the purposes of this discussion hope will be discussed as it relates to life-threatening or life-limiting illness.

Many theories of hope have been built upon the work of Dufault and Martocchio (1985). Taken from data collected from two cohorts of patients (35 elderly cancer patients and 47 terminally ill adults from various diagnoses), they constructed a theory of hope defined by two spheres and six dimensions. Their working definition of hope is “a multidimensional dynamic life force characterized by a confident yet uncertain expectation of achieving a future good, which to the hoping person, is realistically possible and personally significant” (p. 380). There are two main spheres of hope; generalized hope and particularized hope. Generalized hope is broad in scope, not connected to any particular object of hope and is used as a protection against despair, especially when particular hopes are not present. It restores meaning and provides a flexible viewpoint from which to consider possible outcomes. The second sphere is particularized hope in which there is a defined outcome and object hope. It is characterized by specific expectation and becomes the focus of one's energies and efforts (Dufault & Martocchio, 1985). The six dimensions of hope are characterized as 1) affective – processes that focus on the emotion and feeling of hope, 2) cognitive – processes used to think, imagine, interpret and judge hope, 3) behavioral – the actions taken by the hoping person to reach their goals, 4) affiliative – the processes used to determine interconnectedness, involvement or relatedness as it pertains to relationships with others or a deity 5) temporal – the processes used to include the specificity time (past, present, future) as it relates to hope, and 6) contextual – the life situations that

surround and influence hope (Dufault & Martocchio, 1985). Understanding these dimensions can help healthcare providers understand hope and the factors that influence its presence and form.

C.R. Snyder's hope theory was birthed within the field of positive psychology. His theory is that hope "is a cognitive set based on a reciprocally-derived sense of successful agency (goal-directed determination) and pathways (planning to meet goals)" (C R Snyder, 2000). This definition implies an ability to form a plausible route related to the goal and the motivational to move toward that goal. Snyder acknowledges barriers often present themselves in the midst of the route. In this scenario, alternative routes must be considered. While hope is often defined in terms of an emotion that drives activity, Snyder postulates the emotion of hope occurs as a by-product of goal-directed thoughts and activities – perceived success in the pursuit of a goal leads to positive emotions and perceived failures lead to negative emotions (Snyder, 2000; Snyder et al., 1991).

Recently, Bally et al. (2013) employed a grounded theory approach to explicitly explore the parental hope experience in the setting of childhood cancer. Interviews and journals were collected from 13 parents whose children were undergoing active cancer treatment. This work resulted in a theory called Keeping Hope Possible. The overall concern from parents was to not lose hope, thus keeping hope possible emerged as a means by which to explain parents processes and feelings related to hope for their child. Bally identified 4 cyclical sub-processes used by parents to keep hope; accepting reality, establishing control, restructuring hope, and purposive positive thinking. These processes are influenced by various mediating factors of hope identified by parents; ongoing assessment of the child's health, gaining knowledge and experience, connecting with

others, being in the loop, and reaffirming faith. Parents navigated these processes in a recurring and cyclical fashion while vacillating between “hoping for the best and preparing for the worst” (p. 5). This work offers a unique view of parental hope and the work of keeping hope possible.

Barrera et al. (2013) conducted a prospective qualitative study based on grounded theory methodology with 35 parents of children recently diagnosed with difficult to treat cancer (10% or less chance of survival) to ascertain what has become an emerging theory of the tenaciousness and tenuousness of hope among parents. The tenaciousness of hope was facilitated by focusing on the present positive, psychosocial support, and spirituality. The tenuousness of hope was brought on by awareness of the negative effects of treatment or lack of response in their child, negativity from others, physical and psychological exhaustion, information overload, and fear and uncertainty. Interestingly, parents of children with a poor prognosis are able to maintain hope which in turn leads to an ability to maintain function, as well as uphold morale (Barrera et al., 2013).

While many definitions and theories of hope exist, the literature provides a constellation of commonalities. Hope is both complex and dynamic (Barrera et al., 2013; Dufault & Martocchio, 1985; Fitzgerald Miller, 2007; Folkman et al., 1985; Samson et al., 2009). Hope serves as a life-preserver and the source of strength and comfort from which parents navigate the fear and uncertainty of a cancer diagnosis in their child (Bally et al., 2013; Chris Feudtner et al., 2010; Fitzgerald Miller, 2007; Groopman, 2004). Hope is characterized by cognitive, affective, behavioral, affiliative, temporal, and contextual processes (Dufault & Martocchio, 1985; Duggleby et al., 2010; Duggleby, Williams, Wright, & Bollinger, 2009). Guided by the child’s condition and response to treatment,

hope is described as being both tenacious and tenuous in character and may or may not be goal-oriented or particularized (Barrera et al., 2013; Dufault & Martocchio, 1985; Granek et al., 2013). Hope is a multidimensional phenomenon that is highly personal and thus does not lend itself well to any one particular definition or set of characteristics.

Uncertainty

Uncertainty is the hallmark of cancer. It is characterized by a lack of knowing the outcome and the presence of doubt. Uncertain is an adjective defined as “not exactly known or decided; not sure; having some doubt” (Uncertainty, n.d.). This uncertainty manifests itself in parents at all points along the cancer continuum and persists even after the child has been declared cured. Uncertainty is most pronounced when the child’s disease has relapsed (K. K. Boman et al., 2004; K. Boman et al., 2003; Clarke-Steffen, 1993; Hoven et al., 2008; Santacroce, 2001). Uncertainty after a period of remission appears to be most acute as parents have had the fear of relapse confirmed and the concomitant poor prognosis established (De Graves & Aranda, 2008; Lin et al., 2010). This section will provide a description of uncertainty as it relates to parents of children diagnosed with cancer including those with life-limiting or life-threatening illness. Various theories of uncertainty will also be explored.

In the context of pediatric illness, uncertainty has probably been best studied and characterized based on research derived from the work of Dr. Merle Mishel (Lin et al., 2010; M H Mishel & Braden, 1987; M H Mishel, 1984; M. Mishel, 1981, 1988). Mishel (M. Mishel, 1988) defined uncertainty as “the inability to determine the meaning of illness-related events” (p. 225). Uncertainty signals there is either not enough information with which to make a judgment about the meaning of an event or there is an inability to

predict outcomes. Initially, uncertainty itself is a neutral event; it is not until it is appraised that it becomes either a positive or negative event. The outcome of this appraisal leads to one's view of uncertainty as either an opportunity or a threat based on the perceived benefits or harm derived from this uncertainty.

The pervasiveness of uncertainty in undiagnosed illness was demonstrated by Madeo et al. (2012) in a mixed methods study to determine factors that contribute to uncertainty among parents of children with an undiagnosed medical condition. Their analysis determined parents who perceive more uncertainty also perceive less control over their child's illness. Optimism was found to have a negative correlation with uncertainty. Parents who were more optimistic about their child's diagnosis were less uncertain. Perceived disease severity also contributed to uncertainty; the worse the perceived severity of the illness, the more uncertainty parents experienced. Lastly, it was thought greater time since onset of illness might increase uncertainty however no significant correlation was found.

'Waiting and not knowing' was a theme identified in Clark-Steffen's (Clarke-Steffen, 1993) qualitative study of 40 family members of seven children diagnosed with a favorable prognosis cancer (>60% chance of cure). Uncertainty was identified as one of four subtheme's with the others being worry and preoccupation, vulnerability, and helplessness. Many aspects of their child's care were fraught with uncertainty; prognosis (both long and short-term), treatment effects, suffering, and managing the illness while managing the daily life of their families. Families expressed that healthcare workers underestimated the intensity and pain associated with this waiting phase. Also during this time of waiting, families assumed the worst because they were not updated as to the

status of diagnostic test results. In this study, families requested complete honesty about their child's condition despite the uncertainty it might generate.

Pervasive uncertainty endures over the entire treatment-phase of pediatric cancer. In a qualitative study by Stewart and colleagues (2012) looking at treatment related decision-making, parents who were interviewed about their process for making various treatment-related decisions. The overarching theme was 'making the right decision'. Parents accepted the burden of having to make what many felt were potentially life and death decisions (e.g. undergoing a bone marrow transplant) about their child's treatment. This was complicated by uncertainty which intensified the emotional impact these decisions on parents. Lack of knowledge about the disease, treatments, and outcomes contributed to significant uncertainty, especially in the diagnostic phase of the illness. Uncertainty lends profound weight to parental decision-making, which makes it one of the most stressful factors when parenting a child with cancer.

Parents bear the burden of being caregivers of the child whether in hospital or at home. In interviews with parents of 10 children with newly diagnosed cancer, Flury et al. (2011) found that taking their child home after first discharge from the hospital was a frightening experience hallmarked by uncertainty. There were new tasks to take on while caring for their child which changed the whole complexion of their daily life. Slowly, parents began to realize that the child's disease and the unknown future would have an impact on them for the rest of their lives (Flury et al., 2011). Similarly, Bjork and colleagues (2005) interviewed the family members of 17 children with newly diagnosed cancer. Two themes emerged from this study: "a broken life world" and "striving to survive" (p.272). The new diagnosis threw families into a state of chaos, uncertainty, and

broken routines. However, families worked together to define a new normal that incorporates caring for the child and dealing with an unknown future (Björk et al., 2005).

Even when children have successfully completed treatment for their cancer, uncertainty and navigating an unknown future remain for the parents. In a qualitative, grounded theory study, McKenzie and Curle (2012) employed Charmaz's framework to analyze findings acquired through interviews with 11 parents from 6 families whose child was at the end of treatment (EOT) and were transitioning to post-treatment care. The primary emergent theme was "the end is not the end". Managing uncertainty about how to go on with normal lives while dealing with the continued threat of the cancer returning were very present and real fears. Woodgate (2006) also collected narratives from families of children completing treatment. Related themes were found regarding uncertainty in the post-treatment phase. "It's never over with" and "always a waiting game" (p.15) highlight the profound way in which the families view of life had changed after cancer. While trying to maintain a sense of spirit and normalcy, certainty that the cancer was cured was elusive for these families and clouded by the realization life would forever be different.

One of the greatest fears realized by parents is the relapse of disease previously thought in remission or cured. De Graves and Aranda (2008) interviewed twelve families in a critical ethnography exploring the relapse of their child's disease. These families confirmed that hope and uncertainty are inexorably linked. However, unlike newly diagnosed families who find hope in the promise of high cure rates, families who experience relapse reframe and cling to hope as the only alternative to certain death. Families used coping strategies to maintain hope and control their fears. These strategies

involved maintaining normality, living in the moment (not counting on a tomorrow), hypervigilance to their child's treatment and condition, and finding hope and hopeful messages in those around them. As uncertainty increased, and clarity decreased, families were able to move toward palliative care. Hope remains an essential element in living with the reality of uncertainty introduced by relapse. This concept of holding hope along with the fear that accompanies the child's declining health status is further supported by Bally (2013) who found parents both fear the loss of hope but want to keep hope possible. In these families, this was accomplished by accepting reality, establishing control, restructuring hope, and purposive positive thinking.

Coping

Coping has been defined in several ways. The root of coping, cope has been described as a vestment, a covering that protects. As verb, cope and coping mean to "deal with and attempt to overcome problems and difficulties" (Cope, n.d.). Folkman and Greer (2000) define coping as "the thoughts and behaviors that a person uses to regulate stress (emotion-focused coping), manage the problem causing distress (problem-focused coping), and maintain positive well-being (meaning-focused coping)" (p. 12). How one copes can influence the outcome of a stressful situation and ways in which individuals function for years after the situation is resolved (Clayton et al., 2005; Quintana, Wottrich, Camargo, & Cherer, 2013; Reder & Serwint, 2009; Svavarsdottir, 2005).

The diagnosis of cancer immediately launches the family into a barrage of tests, information, discussions, decisions, and treatments. Parents must adapt to a new environment by taking in vast amounts of new information and devising new ways of functioning as a family. In the literature, this has been discussed as adaptation or coping.

Parents of children with a cancer diagnosis struggle with loss of control, poor self-esteem, anxiety, disease-related fear, and depression (Hoven et al., 2008).

The impact of childhood cancer has been evaluated in families whose child has completed treatment for cancer (Van Dongen-Melman et al., 1998). In qualitative interviews with families post-treatment, families describe the impact of the diagnosis on their lives. Parents described an initial shock, followed by a tally of losses to the child, the parents, and the family. Loss of positivity towards life, loss of invulnerability, loss of time, losses of the child's function due to treatment or long-term effects were expressed by parents as negatives of the cancer journey. Some parents described a new outlook on life, making the most of any time given and the impact of this renewed perspective on the relationship with the child, as well as a revaluing of the marriage partnership. Despite positive changes reported, parents continued to persevere about the diagnosis and the way in which it had forever changed their lives.

Pai and colleagues (Pai et al., 2007) performed a meta-analysis comparing function of parents of children with cancer to parents of healthy children. Not surprisingly, mothers and fathers of children with cancer reported greater distress with mothers reporting greater distress than fathers 12 months after diagnosis as compared to parents of healthy children. Mothers of children with cancer also reported higher levels of family conflict than did mothers of healthy children. This study demonstrates the impact of a pediatric cancer diagnosis on the family and the need for psychosocial interventions, especially within the first year.

Factors affecting coping

Multiple studies have evaluated factors enabling or hindering parents' ability to cope with their child's cancer diagnosis. Fear, anxiety, and depression, drive much of the coping response in both mothers and fathers with parents exhibiting higher levels of these factors employing less helpful strategies for coping (Fletcher et al., 2010; Hoekstra-Weebers, Jaspers, Kamps, & Klip, 1999; Hoven et al., 2008; Rosenberg, Baker, Syrjala, Back, & Wolfe, 2013; Wray, Lee, Dearmun, & Franck, 2011). External factors such as social support, family function, uncertainty, and interactions with healthcare providers change the lens through which parents both view the situation and respond to the stressor presented (Rosenberg et al., 2013; Santacroce, 2003; Sloper, 2000; Wray et al., 2011). Faith and spirituality also influence the ability and means by which parents cope with uncertainty and fear surrounding the illness experience (Duggleby et al., 2010; Hexem, Mollen, Carroll, Lancot, & Feudtner, 2011; Salmon et al., 2012). An assessment of coping must also take these factors into consideration.

Coping strategies

Coping as proposed by Folkman (2010) refers to "the thoughts and behaviors people use to manage the internal and external demands of stressful events" (p. 902). Parental coping is a result of the parent's personal appraisal of a situation (Folkman et al., 1986). Mishel's model of Uncertainty in Illness postulates that appraisals result in viewing the stressor as either an opportunity or a threat (Mishel, 1983). Parents who appraise the stressor as a threat envision a negative outcome, a danger to their child. Parents who appraise the stressor as an opportunity are thought to generate an illusion that proposes a more positive outcome.

Mishel (1983) suggests buffering strategies are used to support the uncertainty of the illness if it is beneficial in preserving hope. Buffering blocks the input of any information that could alter the illusion. This is often done by selective ignoring of disparities between healthy children and their child and by denying or minimizing new information that threatens the illusion. Hope has been postulated as a buffer that protects parents from the feelings of fear and anxiety during periods of uncertainty (Folkman, 2010).

Last and Grootenhuis (1997) identified most coping strategies used by parents and children dealing with cancer are protective from negative emotions and generate feelings of control. In their study of predictors of parental adjustment multiple regression models were built to evaluate coping strategies used and levels of anxiety, depression, loneliness, helplessness, and uncertainty. Parents used a combination and series of secondary control strategies to deal with their child's diagnosis. These strategies consisted of vicarious control (attributing power to healthcare provider), illusory control (relying on luck and wishful thinking), predictive control (expectations) and interpretive control (having knowledge). Negative predictive control (negative expectations) was the most important predictor of negative emotions for both parents. Positive expectations were protective from negative emotions.

Pai and colleagues (Pai et al., 2007) performed a meta-analysis comparing function of parents of children with cancer to parents of healthy children. Mothers and fathers of children with cancer reported greater distress with mothers reporting greater distress than fathers 12 months after diagnosis as compared to parents of healthy children. Mothers of children with cancer also reported higher levels of family conflict than did

mothers of healthy children. This study demonstrates the impact of a pediatric cancer diagnosis on the family and the need for psychosocial interventions, especially within the first year.

When comparing coping strategies used by parents of children with cancer versus strategies used by parents of healthy children, no difference was found between groups (Norberg, Lindblad, & Boman, 2005). Parents using more active, problem-focused strategies had less distress in parents of children with cancer. Passive coping was significantly related to emotional distress accounting for about 25% of the variance in the overall analysis. Expression of negative emotions was associated with increased distress. This study also indicated coping strategies that were initially helpful became less effective over time.

Hope & Uncertainty

In the presence of uncertainty, parents engage hope as a vital resource. Often, nurses report parents feel unrealistically hopeful because they do not have the full prognostic picture (Feudtner et al., 2007). Mack and colleagues (2007) in their study of 194 parents in the first year out from diagnosis found that overall, parents who believed they were given full prognostic disclosure reported high levels of communication-related hope. This high level of hope was present regardless of the child's likelihood of a cure. This supports a practice of open-communication between parents and the physician which in turn leads to trust and the maintenance of hope despite prognosis.

Hope waxes and wanes over time as treatment progresses and the child's illness either responds or worsens. Uncertainty intensifies when the prognosis becomes poor. Barrera and colleagues (Barrera et al., 2013) interviewed 35 parents of children with

difficult to treat cancer approximately three months after diagnosis. Findings across all parents revealed hope was directly related to parents' desire their child have a future, belief that treatment would be effective, and the child would survive despite the poor diagnosis. The overarching theme was the while hope could be robust and tenacious at times, it could quickly become tenuous and fragile. Parents tried to avoid losing hope if at all possible. This fits well with Bally et al. (2013) who interviewed and reviewed journals of 16 parents whose children were in active treatment for cancer. Parents expressed the need to 'keep hope possible' no matter the circumstances. Hope was described as "an inner guide" (p. 5), providing them with strength for the tasks at hand and allowing them to grow through the process of caring for their child.

Relapse reveals yet another layer of uncertainty for the parent of the child with cancer. De Graves & Aranda (2008) conducted a critical ethnography with twelve families whose child had relapsed. Each family was interviewed at length an average of 4 times over a span of 6 to 13 months. The purpose of this study was to explore the experience of families when their child had relapsed. Families in this study experienced profound uncertainty when their child's disease relapsed. At diagnosis most families believed their child would be cured. Fighting for a cure while hoping for the best was a survival mechanism used to endure the uncertainty of the relapse. There was an interesting juxtaposition of the uncertainty due to relapse creating the possibility of hope yet the lack of certainty of impending death keeping hope alive. Uncertainty allowed parents to avoid the reality their child could die. Interestingly these authors point out this may explain why even at end of life, parents can often still maintain hope, even if it's not

for a cure. Clearly uncertainty sets the stage for hope. Both of these factors play a major role in how parents navigate the cancer diagnosis and cope with the outcomes.

Hope & Coping

While much of the extant literature on parents dealing with a child's cancer diagnosis proposes that hope is an important element for coping with the disease, there is little literature directly studying the role of hope in coping. Eapen and Revesz (2003) evaluated psychological correlates and illness variables with ways of coping in 38 children in the United Arab Emirates. As part of the study, parents of the children were interviewed to gather demographic, family information, and a questionnaire to evaluate parental coping strategies. Less than optimal parental coping was significantly associated with poor family functioning, behavioral and emotional problems in the child, and parental lack of hope. Wong and Chan (2006) employed phenomenology to examine the experience of nine parents of children diagnosed with cancer. Four major themes appeared describing parents coping experience; shock and denial, establishing meaning, confronting reality, and establishing a new perspective. Parents identified "establishing hope" as part of gaining a new perspective to help cope with the diagnosis and treatment.

In considering how hope and coping are related at end of life, Kars et al. (2010) conducted interviews with 44 parents of children whose cancer was deemed no longer curative. These interviews took place anywhere between two days and one year prior to death of the child. Two major themes emerged: preserving life and letting go of their child. Parents wavered between the two as the disease progressed. Uncertainty was a factor in preserving life and certainty about the progression of the disease was factor in letting go. A factor that modulated between the two themes was hope. All parents hoped

for a positive outcome despite their child's poor prognosis. Hope often changed over time from hope for a cure to hope for a peaceful death. Interestingly, parents used hope to "make the certain uncertain" (p. 1006). This perpetuated the use of life-prolonging and experimental treatments to delay the certainty of death.

Lastly, hope has been studied through the perspective of decision-making by bereaved parents and the healthcare providers who cared for their child (Reder & Serwint, 2009). In focus groups, participants were asked to define hope and describe its role in decision-making. Two major themes emerged from these groups; balancing hope with accepting reality and balancing hope without prolonging the patients suffering. In terms of coping, healthcare providers valued hope as a coping mechanism and understood its role in helping parents survive the process of losing their child. Parents felt they were 'bearers of hope' and as parents they could not give up hope. Both groups acknowledged hope changes over time and even at death hope can exist, even if it's hope for a peaceful death. The researchers suggest healthcare providers must take into account the parents' view of hope and their perceived role as bearers of hope, helping them to hope for the best while preparing for the worst.

Uncertainty & Coping

Much of the literature surrounding parenting a child with cancer recognizes the importance of parents coping with the uncertainty of the diagnosis as it relates to the health of the parent, the child, and family function. However, little actual research exists to describe or measure coping along with uncertainty.

Research outside of pediatric cancer has found parents cope with uncertainty differently based on the child's diagnosis and prognosis. Madeo et al. (2012) assessed

uncertainty both quantitatively and qualitatively in 209 parents of children affected by a medical condition remaining undiagnosed for 2 or more years. Parents who perceived less control over their child's condition were less optimistic and had higher ambiguity and lack of clarity on the PPUS scale. These results were confirmed by qualitative findings as parents identified strategies to cope with the condition and uncertainty surrounding it. Major themes identified were information and decision making about care, advocacy, child's comfort and self-care. Parents struggled to cope with the uncertainty and since diagnosis was unknown they found difficulty finding support from other parents and healthcare providers.

In a study of parents of critically ill infants, Erickson (1988) found quantitatively parents with high levels of uncertainty used emotion-focused coping (wishful thinking, self-blame). However, qualitatively, parents used problem-focused strategies. It was thought that timing of questionnaires played a role in giving parents time to formulate a response to the threat of their child's illness, thereby using more problem-focused strategies once the child's illness was established.

Patistea (2005) examined appraisal of health and coping in a cohort of parents (41 mothers and 31 fathers) of children with leukemia in Greece. The majority of parents appraised their child's illness as a threat. The Coping Health Inventory for Parents (CHIP) scale was used to measure parental coping. Parents who used a higher number of coping strategies scored better on measures of maintaining family integration and social support, strengthening self, and understanding and mastering medical information needed to understand and deal with their child's illness. Lin (2007) studied Taiwanese parents whose child was being treated for cancer. This study employed the Parental Coping

Strategies Inventory (PCSI) to measure coping and the PPUS to measure uncertainty. Parental uncertainty was related to perceived social support and child's health status. Parents of children with relapsed disease exhibited higher uncertainty than those in remission. Parent education level had no effect on uncertainty, however in this sample >80% of parents had a high-school degree or above. Lower parental certainty was associated with higher coping and higher coping was associated with higher psychological growth.

Uncertainty and coping have also been studied based on parental role. Sterken (1996) studied 31 fathers whose children were in treatment for cancer. Younger fathers exhibited higher uncertainty than older fathers and used optimistic, evasive (avoidant activities) and emotive coping styles. Overall uncertainty was greater with fathers using a less confrontive coping style and when they were experiencing high emotions. Fathers who demonstrated high level of self-reliance had less uncertainty. The author postulates this may be due to male stereotype of self-reliance and emotional bankruptcy. Father's should let their needs be known to engage healthier modes of coping.

Parents of children with cancer struggle with the end of treatment. They are no longer being watched, monitored, or followed as closely as when their child was in active treatment and this transition is difficult (De Graves & Aranda, 2008; Grootenhuis & Last, 1997; Hobbie et al., 2010). McKenzie and Curle (2012) conducted a grounded theory inquiry to gain insight into the transition from active treatment to end of treatment (EOT). They interviewed 11 parents representative of 6 families. The prevailing theme that emerged is 'the end is not the end'. In this process, families identified coping strategies that helped them manage the transition; one day at a time, avoiding negative thoughts,

relying on increased support from healthcare providers, as well as family and friends. Parents felt they had to adjust their coping strategies deal with the competing themes of ‘life is very normal’ and yet ‘it’s not going to go away’. Parents used strategies such as focusing on positivity, taking one day at a time, avoiding negativity.

Conceptual Framework

The conceptual framework used for this study is Mishel’s model of Perceived Uncertainty in Illness. This model is based on a cognitive appraisal model and incorporates the work of several theorists (Mishel, 1981). Factors both within the person and characteristics of the event causing stress (stimuli) influence the perception of illness-related events. Initial appraisal occurs when a person assigns meaning to the stimuli. Uncertainty occurs when the individual is unable to assign meaning and value to events and is unable to predict outcomes (Mishel, 1984). This model has been revised over time. The model used for this study is derived from the model description found in Uncertainty in Illness (Mishel, 1988). See Figure 1: Theory of Uncertainty in Illness.

Stimuli Frame

The primary antecedent variable in the model is stimuli frame. The stimuli frame consists of three components: symptom pattern, event familiarity, and event congruence. In children with cancer, a change in symptom pattern is often needed before parents recognize and believe there is either a worsening of the condition or an improvement (Pritchard et al., 2008; Santacroce, 2001). Parents use the stimuli to construct a cognitive schema for the disease which decreases uncertainty. The stimuli frame is influenced by two variables: cognitive capacity (the ability to process information) and structure providers (resources available to help interpret meaning of the stimuli). Structure

providers in this model are educational level, social support, and credible authority of healthcare personnel.

Symptom pattern. When symptoms occur in a pattern, there is less uncertainty. An example of this might be a child who becomes cranky, tired, and ill with nausea after receiving chemotherapy. Parents process this information in the context of their own experiences, cultural, and social cues along with information from healthcare provider. Symptom appraisal can be hindered when symptoms lack prominence.

Event familiarity. This refers to the repetitive nature of the structure environment. Familiarity is a result of cognitive processes based on experience with the environment. New and novel symptoms or treatments threaten familiarity, such as at diagnosis or at end of life as the child declines. During treatment, parents do become familiar with the various treatments required for their child.

Event congruence. Event congruence is when there is consistency between what is expected and what occurs. Lack of congruence from expectations creates questions and undermines the predictability established. Parents who anticipate an admission for chemotherapy will experience a lack of congruence if the child ends up being treated for a blood infection instead.

Cognitive capacity. This refers to the ability of persons to process information. When the environment is perceived as a threat, cognitive efficiency is diminished and the ability to further process cues is impaired. The parent who was just told their child has leukemia during an emergency department visit for bruising will experience decreased cognitive processing requiring much repeat information.

Structure Providers

Education. Education has both a direct and indirect effect on perceived uncertainty. Education provided can improve the parent/patient's knowledge about the stimuli frame which helps provide meaning and understanding. Educational level also plays a role in the ability to modify uncertainty cognitively. Individuals with less education demonstrate higher levels and longer periods of uncertainty due to a lack of ability to understand complex treatments and rationale for care.

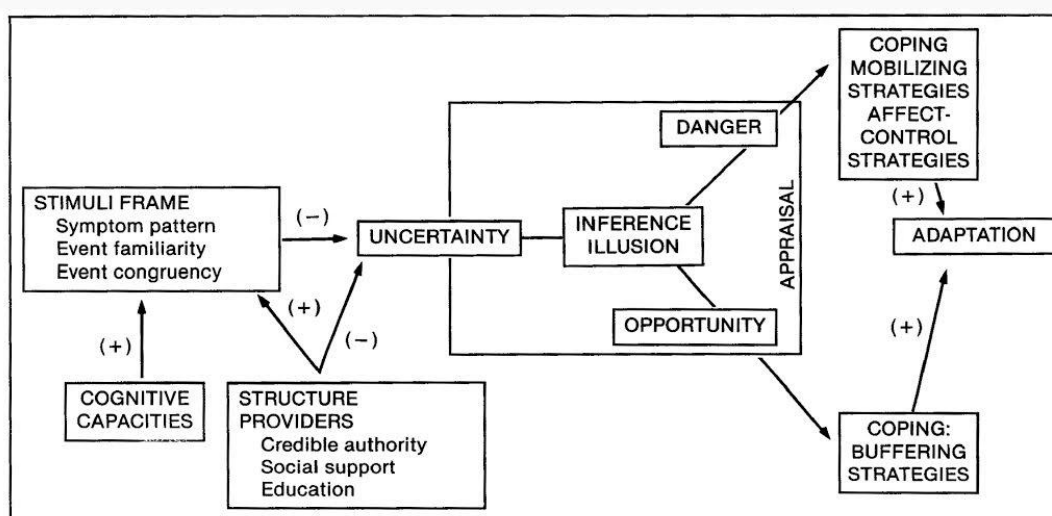
Social Support. Social support reduces uncertainty by acting as a feedback system to help interpret the meaning of illness-related events. Social support reduces uncertainty by modifying a) the ambiguity of the illness, b) the perceived complexity of the treatment, and c) the unpredictability of the future. Having someone to share information with assists in the appraisal process (Mishel & Braden, 1988).

Credible Authority. Credible authority is the amount of trust and confidence patients or caregivers have in the ability of healthcare providers to provide care. Trusted, consistent information provided to families and caregivers enhances event familiarity, and promotes event congruence. This directly supports the structure of the cognitive schema families build. Nurses have multiple opportunities to be credible authorities to patients. Trusting relationships with healthcare providers have been found to reduce uncertainty (Mishel & Braden, 1987).

Appraisal of Uncertainty

Events are perceived as uncertain when a) the event is not recognized, b) the event is recognized but not classified, or c) the event is recognized but classified incorrectly. Inference and illusion are used to complete the appraisal process. Inference is based on beliefs, personal disposition and learned interaction with the environment. Illusion is defined as belief constructed out of uncertainty. Illusion can be fostered by significant others, healthcare providers and can be both positive and negative to functioning.

An appraisal will result in uncertainty being viewed as either a danger or an opportunity. Loss or absence of a credible authority can lead to a danger appraisal in which uncertainty stimulates a fight or flight response. When danger is appraised, a coping response is needed so that it can be reframed into a positive illusion. When effective, coping strategies will lead to adaptation. Adaptation is defined as “a biopsychosocial behavior occurring within person’s individually defined range of usual behavior” (M. Mishel, 1988, p. 231).



From “Uncertainty in illness”, Mishel, M.(1988), Journal of Nursing Scholarship, 20(4), p.226.

Figure 1. Mishel’s Uncertainty in Illness model

Conclusion

In this chapter both definitions and theories of hope, uncertainty, and coping and a review of the pertinent literature as it relates to parents of children with cancer was presented. Relevant research on the topics under study has been discussed and a conceptual framework presented. While much literature exists regarding parents of children with cancer, most of this data is qualitative. A quantitative study of hope, uncertainty, and coping may provide veracity and further support for the importance of these concepts in caring for parents and their children who are being treated for cancer.

Chapter 3

Methodology

The purpose of this study was to examine relationships between levels of hope, uncertainty, and coping among parents of children with cancer. Gaining a clearer picture of the relationship between hope, uncertainty, and coping in parents may offer healthcare providers further insight into potential factors that influence caregiver behaviors while caring for their child with cancer. Mishel's model of Uncertainty in Illness (M H Mishel, 1981) guided the selection of study variables, the patient population, and the study design. This chapter provides research aims and questions, a description of the design, setting, sample used and sampling criteria, data collection, and analytic procedures. Human subjects' protections are also discussed.

Research Questions

Three research questions guided the design, implementation, and analysis of this study.

1. What are the socioeconomic and demographic characteristics that define the caregivers of children with cancer in this population?

2. What are the demographic and disease characteristics of children in this population undergoing treatment for cancer?
3. What are the relationships between levels of hope, uncertainty, and coping among caregivers in this population?

Study Aims

- Aim 1. Describe a sample of parent/child dyads of children with cancer receiving services at a large, academic pediatric healthcare center in southern California.
- Aim 2. Examine the relationships between hope, uncertainty, and coping among a sample of parent/child dyads of children with cancer receiving services at a large, academic pediatric healthcare center in southern California
- Aim 3. Examine the influence days since cancer diagnosis, parent relationship status, parent relationship to child, parent education, child disease status, hope, and uncertainty on coping.

Study Design

A descriptive, correlational, cross-sectional design was used for this study. The concepts under study have been explored qualitatively, however this assemblage of variables (hope, uncertainty, and coping) had not yet been quantitatively measured in this particular population (Bally et al., 2013; Kylma & Juvakka, 2007; Kylma & Vehvilainen-Julkunen, 1997; Salmon et al., 2012). A descriptive design was appropriate as little is known about the relationships between hope, uncertainty, and coping in this population. According to Polit & Beck (2012), the purpose of a descriptive, correlational design is to

describe naturally occurring relationships among variables rather than to look for causality. Study variables must be clearly identified and described in detail. This design facilitates the identification of many interrelationships among variables in a situation in a short time. Descriptive correlational studies are also used to develop hypotheses for future studies. In this research design, no attempt is made to control or manipulate the situation. Given the unknown prevalence or relationships of the phenomena under study, a descriptive design was most appropriate.

Setting

This study was conducted at a single, comprehensive, pediatric cancer center located in southern California. This center treats several hundred diverse pediatric cancer patients per year coming primarily from residences in the surrounding counties. Approximately 200 newly diagnosed patients are evaluated and treated annually. The center follows nearly 400 children for ongoing and active treatment, as well as 650 children who are off-therapy and being followed for long-term survival care and side-effects. Each year, approximately 20 children receive autologous, allogeneic, and matched unrelated donor bone marrow transplants. The center includes a 40-bed inpatient unit (which includes a 5-bed bone marrow transplant unit) and a busy outpatient treatment center which includes examination rooms, an infusion center for the administration of fluids, chemotherapy and blood products, and a procedure room for bone marrow biopsies and lumbar punctures. This clinic sees approximately 80 outpatients per day. According to the California Cancer Registry (CCR) the population in Imperial County is 70% Hispanic while the population of San Diego County is

approximately 55% Hispanic (CCR, 2011), resulting in a large Hispanic population being treated for cancer at this site.

Sample and Sampling

A convenience sample was used for this study. The participants were parents of children (ages 0-21) undergoing treatment for cancer. Participants had to meet the following inclusion criteria to be eligible a) parent of a child being treated for cancer, b) blood relative or step-parent living with child $\geq 50\%$ of time or status as the custodial guardian, c) age 18 years or older, and d) ability to read and communicate in either English or Spanish. Parents were excluded from participation if their child did not have a diagnosis of cancer or did not meet the other elements of the inclusion criteria. Only caregivers as defined by inclusion criteria were eligible for participation in this study. Participation in this research was completely voluntary. Parents were assured participation or refusal to participate would in no way affect the care given to the child or the family. In addition to the key study measures, demographic and disease status data were collected for the child receiving treatment. This was accomplished by extracting the data from the electronic medical record (EMR). Parents signed a specific waiver of HIPAA to allow the researcher access and collection of this protected health information.

Power, Effect, and Sample Size

Based on the extant literature conducted on the study concepts, the researcher decided to assume the use of a multivariate regression model to determine the approximate number of participants needed for this study. Proposing the use of ten predictor variables, a moderate effect size ($R^2 = .13$) and a power of .80 with $\alpha = .05$, a

sample of 119 parent-child dyads were required. This power analysis was based on Table 18.4 in Polit & Beck (2012). Given this number of participants there is a 5% chance of a Type I error and a 20% chance of a Type II error. The recruitment goal for this study was 120 parents.

Study Measures

The variables under study were hope, uncertainty, coping, as well as demographic information for both the parent and their child, and disease characteristics of the child.

Hope

Hope was measured using the Herth Hope Index (HHI; Herth, 1992), a 12 item instrument which uses a 4-point Likert-type scale. Participants indicate the degree to which they agree (Strongly Agree or Agree) or disagree (Strongly Disagree or Disagree) with each statement (e.g. "I have a positive outlook on life."). The higher the overall score, the higher the level of hope. This instrument was initially tested on a convenience sample of 172 adults and demonstrated a Cronbach's $\alpha = .91$ with a 2-week test – retest reliability of 0.91. Criterion related validity was established by correlating the HHI with the parent scale, the Herth Hope Scale (Herth, 1992). Since its creation, it has been used in several studies. Construct validity is supported through factor analysis. This index takes no more than 5 minutes to complete.

Uncertainty

Uncertainty was measured using the Parent Perception of Uncertainty Scale (PPUS, Mishel, 1983). The PPUS is a 31 item, 5-point Likert-type scale used to measure a persons' evaluation of their uncertainty experienced concerning another's illness

(Mishel, 1983). Participants indicate the degree to which they agree (Strongly Agree or Agree), are undecided or disagree (Strongly Disagree or Disagree) with each statement (e.g. “I don’t know what is wrong with my child.”). The higher the overall score, the higher the level of uncertainty. This instrument has been used in over 100 research studies and demonstrates an overall Cronbach’s $\alpha = .90$ (citation). Construct validity has been demonstrated through factor analysis and has been supported by numerous studies. This scale takes no more than 5 minutes to complete.

Coping

Coping was measured using the Ways of Coping Questionnaire (WOCQ). The WOCQ is a 66 item, 4-point Likert-type scale that measures types of coping strategies used. Participants indicate the degree to which they have used a particular strategy, 0 = “does not apply/not used, to 3 = “used a great deal”. An example item is “I tried to analyze the problem to understand it better.” The WOCQ consists of 8 subscales that measure different forms of coping; confrontive coping, distancing, self-controlling, seeking social support, accepting responsibility, escape-avoidance, planful problem solving, and positive reappraisal. Each scale has its own Cronbach’s α . Alpha’s range from .61 - .79. The WOCQ has face validity based on the coping strategies reported by individuals coping with the demands of stressful situations. Construct validity has been demonstrated by study results which are consistent with theoretical predictions. Since individuals vary their coping efforts based on their individual situational appraisal of control, measuring construct validity is difficult (Folkman & Lazarus, 1988). This scale takes no more than 15 minutes to complete.

Two additional data collection forms developed by the investigator were used to obtain a) demographic information from the parent (age, gender, personal relationship status, relation to child, ethnicity, race, educational level and number of dependent children – other than the ill child and b) demographic information about the child and characteristics of the child's disease (date of birth, gender, type of health insurance, diagnosis, date of diagnosis, current disease status and current treatment) – these items were abstracted by the researcher from the electronic medical record for accuracy. These variables were chosen based on the results of previous studies demonstrating some correlation with the primary outcome of coping. Health insurance was used as a proxy for socioeconomic status (Health et al., 2004).

Due to the large Hispanic population in this geographic area, permission was sought and granted by the authors of the HHI, the PPUS, and the WOC to translate each of the measures into Spanish. The translation was performed by a native Spanish speaker who is fluent in English and has much experience translating various study measures. The translations were independently reviewed by three individuals (professional translator and parent liaisons), all native Spanish speakers who are all fluent in English. Each of these individuals works daily interacting with and performing translation for the population under study and was highly familiar with the study variables. Each reviewer compared the translation against the original English version and verified the accuracy and appropriateness of the translated measures for this population. These measures were also reviewed and approved for use by the approving human subjects committee.

Procedures

Prospective parent participants were identified by the researcher through a variety of means. A daily review of patient visit boards, along with the assistance of the charge nurse helped identify disease eligible inpatients. Once identified, the researcher reviewed the list to determine appropriateness of interaction with the patient and their family. If patients and families were having a difficult day or had recently received bad news, the researcher avoided approaching these families for recruitment. If the charge nurse deemed the timing appropriate, the researcher then approached the family. Parents were given information regarding the study and allowed time to consider their participation. Most families immediately agreed to participate.

Parents were also recruited in the outpatient clinic where patients come to see the healthcare provider, have labs drawn, and receive needed therapies (chemotherapy, blood products). The researcher would contact the charge nurse to identify eligible families coming into the clinic that day who would have time for participation. After identification, the Parent Liaison (PL), an employee of the care center, would introduce the researcher to the family and provide translation for Spanish-speaking families if needed. Parent Liaisons are parents of former pediatric cancer patients (either living or deceased) whose children received treatment for cancer at the facility. Both PL's working in this center are well-known to these families and provide information and multiple services for the child and family, as well as medical translation (Spanish) as needed. About 2/3 of the participants in this study were recruited in the outpatient clinic.

Once eligible parents were identified, the researcher provided a brief explanation about the study, offered individuals the opportunity to participate, and allowed them time to consider participation. Most families immediately agreed to participate. Participants were reassured that they could decline or stop participation at any point before, during, or after completion of the study questionnaires. Interested participants had all their questions answered and were then given the study packet which included 1) informed consent 2) an adult Waiver of Health Insurance Portability and Accountability Act (HIPAA) form, and 3) the study surveys. Copies of the consents were given to all parents and were also filed in the child's medical record.

Parents who consented to complete the questionnaire were given a \$10 cash gift to acknowledge their contribution of time and effort to the study and to mitigate the risk of survey fatigue (109 questions total). This gift was not mentioned during the recruitment process to avoid undue pressure to participate. Participants who did not turn in a completed questionnaire packet were still allowed to keep the \$10 acknowledgment. A few parents declined the \$10 stating they did not need this in order to participate and just wanted to share their experiences. A participant log was maintained during the study to document the names of parents who were approached, the number who accepted, the number who declined, and the number who actually completed the data. There existed potential for participants to become distressed or upset when answering the questions in the study however, parents did not experience obvious significant psychological or emotional distress while completing the surveys. Most parents verbalized gratitude for

the opportunity to participate, and reported the questionnaire taking only 15-20 minutes to complete.

One hundred and twenty-five parents were approached to participate in this study. Two parents declined stating “now was not a good time”, one parent wanted to participate but did not understand English or Spanish well-enough to participate (Thai), and two parents agreed to participate in the study but did not turn in the study questionnaire prior to discharge from the hospital.

Once the questionnaire was complete, all data were placed in a locked file cabinet in a locked office. Consent forms and waivers were stored separately from questionnaires to ensure anonymity. Each questionnaire packet was assigned a sequential study number as a means of identification and this number was entered on the appropriate record on the participant log. All other study-related documents were stored in a locked file cabinet at the study site and were accessible only to the principal investigator and co-investigators. De-identified data was sent to the statistician for analysis and all results are reported in aggregate. The researcher maintained the original documents in a locked file cabinet within a locked office.

Data Analysis

The Statistical Package for Social Sciences (SPSS) version 22 was used for data analysis. The data was coded and entered by a single analyst who created the SPSS database for this study. Overall scores and subscale scores were computed for the PPUS, HHI, and WOC. For WOC both overall scale and each subscale raw scores and relative scores were calculated. Raw scores are the sum of scores for each of the eight types of

coping. High raw scores indicate that the participant often used those behaviors in coping. Relative scores describe the proportion of effort represented by each type of coping and are expressed as a percentage (Lapp & Collins, 1993). Each raw score is divided by the number of items in the scale to determine the average response. All average responses are summed across the 8 scales. The average score from each scale is then divided by the sum of the averages for all 8 scales to achieve a relative score for the scale (Folkman & Lazarus, 2011). Although frequencies, descriptives, and correlations were run with both raw and relative scores, only raw scores were used in the multivariate analysis as there is some speculation that relative scores introduce artifact into the analysis that can affect results (Lapp & Collins, 1993).

Data evaluation was conducted to look for outliers, miscoding, missing data, and irregularities. A search for outliers determined outliers identified were indeed true values and comprised less than 5% of the overall data. Since some of the variables were not normally distributed and the sample was large, a decision not to transform the outliers was made. The researcher was able to clarify and resolve most of the missing demographic data identified. Assumptions were verified for each test used.

Descriptives

Descriptives and histograms were run for ratio variables (parent age, child age (years), number of dependent children, days since cancer diagnosis, PPUS score, HHI score, and WOC scores. Data was evaluated for skewness and kurtosis; Parent age, child age (years), number of dependent children, # days since cancer diagnosis, and HHI were not normally distributed based on Kolmogorov-Smirnov values of $<.05$. Q-Q plots and

histograms further suggested these variables were not normally distributed with the exception of child age (years) which does appear normally distributed. Frequencies were also run for language of questionnaire, parent gender, parent relationship status, relationship to child (e.g mother vs. father, etc), parent ethnicity, parent race, parent highest education level, child gender, child health insurance, diagnosis, current disease status, and current disease treatment.

Bivariate analysis

Bivariate analyses were conducted using Pearson's r for normally distributed variables of child age, number of dependent children, PPUS score, and WOC score. Spearman's Rho was conducted for variables with non-normal distribution (parent age, number of days since cancer diagnosis, number of dependent children), and HHI score.

Independent sample t-tests were used to examine the difference in means of categorical variables (parent language, parent gender, parent relationship status, parent ethnicity, and child gender). One way ANOVA was used to evaluate categorical variables with 3 or more categories (parent relationship to child, parent race, parent education, child health insurance, child cancer diagnosis, child current disease status, and child disease treatment). Post-hoc tests were conducted using the Tukey honestly significant difference (HSD) test. The Levene's statistic was used to determine homogeneity of variance and found to be non-significant. Once equal variance was determined, the correlation coefficients for the ANOVAs were evaluated for significance.

All assumptions for the procedures used in bivariate correlation were met. Significant correlations were used to build a multivariate regression model. Multiple

regression allows the researcher to use multiple variables with different measurement units to predict the dependent variable (D.F. Polit, 2010) .

Prior to conducting a multivariate analysis, subscales were calculated for the PPUS and the WOC questionnaires. Tests for normality and outliers were conducted on subscale scores. Several outliers were found in the sub scores for both PPUS and WOC, however all scores were verified for accuracy and left in the analysis. The appropriate bivariate analysis (parametric vs. non parametric) was performed based on normality. Assumptions for both t-tests and ANOVAs were met and post-hoc examination revealed equal variances among comparisons except the PPUS lack of clarity subscale which demonstrated a significant result on the Levene's test. These results will be further discussed in Chapter 4.

Multivariate Regression

To examine the influence of the variables on the outcome variables of (1) Hope; (2) Uncertainty, and (3) Coping, multiple regression was performed. Regression techniques make use of the correlation between variables and permit predictions to be made from some known evidence to future events (Munro, 2005). Simultaneous multivariable regressions were computed for the purposes of this study. As there was no random assignment among the participants, potentially confounding variables were controlled.

Hope. A multivariate regression model was built to examine the influence of HHI score using days since cancer diagnosis, parent relationship status, parent relationship to child, parent education, child disease status, PPUS score, and WOC score. Categorical

variables were dummy coded to create dichotomous variables for the analysis. Tests for multicollinearity (Pearson r and Durbin-Watson statistic) indicated no shared variances, so independent observations were assumed. Uncertainty was the largest contributor to the model.

Uncertainty. A multivariate regression model was built examine the influence of PPUS score using days since cancer diagnosis, parent relationship status, parent relationship to child, parent education, child disease status, HHI score, and WOC score. Categorical variables were dummy coded to create dichotomous variables for the analysis. Tests for multicollinearity (Pearson r and Durbin-Watson statistic) indicated no shared variances, so independent observations were assumed. Hope was the largest contributor to the model.

Ways of coping. A multivariate regression model was built to examine the influence of WOC score using days since cancer diagnosis, parent relationship status, parent relationship to child, parent education, child disease status, PPUS score and HHI score. Categorical variables were dummy coded to create dichotomous variables for the analysis. Tests for multicollinearity (Pearson r and Durbin-Watson statistic) indicated no shared variances, so independent observations were assumed. However, the model was not significant for predicting coping. The only variable reaching significance was number of dependent children.

Human Subjects Protection

This study was approved by two separate institutional review boards (IRB), one by the medical center where the study was conducted and one by the university attended

by the investigator. Initial approval was granted in September of 2013 however changes to the study (the inclusion of Spanish translations) and impending study expiration required a second submission with revisions approved in August of 2014. Study recruitment was conducted between January 2014 and February 2015. Participation in the study was completely voluntary. Risk to participants was minimal and included the risk of upsetting emotions as a result of completing the survey and risk of loss of confidentiality. Steps were taken to immediately de-identify data and all data was stored in a locked office. Copies of informed consent were placed in the child's medical record and a copy was given to each participant. Per institution policy, the investigator retained all original documents in the study files.

Chapter 4

Results

The purpose of this study was to examine relationships between levels of hope, uncertainty, and coping among a group of parents of children with cancer. This chapter provides a brief overview of the recruitment of the participants, analyses conducted, the reliabilities of the study measures as determined for this sample, and lastly a general summary of the findings will be presented.

Participants

Participants for this study comprised a convenience sample of 120 parents recruited from a large pediatric cancer center at a single children's hospital in Southern California, from January 2014 through February 2015. Parents were identified through a patient list maintained by the hospital's electronic medical record (EMR) based on their child's cancer diagnosis. Once identified, parents were approached by a study team member who, in consultation with the registered nurse assigned to the child to ensure families were not disturbed, handed them a study information sheet and explained the study. Parents were eligible to participate if they were English or Spanish speaking, 18 years of age or older, and had a child currently being treated for a hematologic or oncologic malignancy at the target hospital. Parents were included in the study if they were a biological parent,

adoptive parent, step-parent, blood relative, or permanent legal guardian who lived with the child more than 50% of the time. As part of the study, demographic and health-related data from 106 children's EMR were extracted. Those parents whose adult child (18 years or older) did not consent to the data extraction were excluded from the study. Upon providing written informed consent, one to two parents per child were given a self-administered questionnaire to complete at the hospital or at a private location of their choosing. Participants could also elect to have a study team member administer the questionnaire. After the questionnaire was completed, a study team member extracted the child's study data from the child's EMR. All participants received \$10 dollars as an acknowledgment for their participation whether they completed the questionnaire or not. All procedures were approved by the university and target hospital institutional review boards for the protection of human subjects.

Analyses

Analyses for all variables were performed on 120 cases. For those parents who shared the same child ($n = 28$), the data points extracted from the child's EMR were exactly the same. Descriptive statistics were used to measure frequency and measures of central tendency. Pearson and Spearman correlations were used to describe the bivariate relationships between the continuous and categorical study variables. Independent t-tests and one-way ANOVA's were used to examine bivariate relationships between participant characteristics and the continuous outcome variables (i.e., MUIS, HHI, and WOC scores). A multivariate linear regression analysis was conducted with variables: 1) significantly associated in the bivariate analysis ($p < .05$) or 2) had substantive theoretical

importance. No assumptions were made about the order in which variables were entered.

Data analysis was carried out with IBM SPSS version 22.0.

Aim 1

Describe a sample of parents and children with cancer receiving services at a large, academic pediatric healthcare center in southern California.

One-hundred and twenty parents completed the questionnaire; 89 were female with all but four being mothers of the child being treated for cancer (4 females were custodial guardians). The mean age of all participants was 39.5 ± 10 years.

Approximately 80% of parents were in a committed relationship versus being single (20%). Slightly more than half (50.8%) of the sample population identified ethnicity as Hispanic/Latino, 74% completed the questionnaire in English, 26% completed the questionnaire in Spanish. The majority of participants (81.4%) had completed a minimum of some college/trade school, 20% reported completing a graduate or doctoral degree. Parents had an average of 1.7 ± 1.3 dependent children (not including the child with cancer). Child demographic and health-related data were extracted from the child's EMR for each of the 120 parents; 28 parents shared the same child-related data. Table 1 summarizes the sample characteristics for 120 parents.

Table 1

Demographic Characteristics – Parents

Characteristic	<i>n</i>	%
Age, mean (range), years SD	39.5 (22 – 73), 10	
Gender		
Male	30	25
Female	89	74.2
Relationship to child		
Mother	85	70.8
Father	27	22.5
Custodial guardian/Other	8	6.6
Relationship status		
In a committed relationship	94	80.3
Single	23	19.7
Ethnicity		
Hispanic/Latino	61	50.8
Non-Hispanic	59	49.2
Race		
American Indian/Alaska Native	1	0.8
Asian	7	5.8
Black or African American	6	6.1
Native Hawaiian/Other Pacific Islander	3	2.5
White/Caucasian	63	52.5
Other ^a	19	15.8
Highest Level of Education Completed		
Less than 12 th grade	22	18.3
High School or GED	15	12.5
Some college or trade school	30	25
Associates Degree (2 year)	5	4.2
Bachelor of Science or Arts (4 year)	22	18.3
Graduate or doctoral degree	24	20
Number of dependent children (other than ill child), mean (range) SD	1.7 (0-5)	

^a Fifteen parents (15.2%) labeled themselves as Other = “Mexican” or “Hispanic/Latino”

Note. Values expressed as *n* (%) unless otherwise noted. Percentage may not add up to 100% due to missing data or rounding.

The mean age of the child observed in this study was approximately 8 ± 5.2 years old. There were more males ($n = 57$) than females ($n = 48$), 1 missing value. Nearly 43% of the sample was covered by Medi-Cal insurance. Medi-Cal is the state’s insurance

for low income individuals and their dependent children (California Department of Health Care Services, 2015). Medi-Cal is the equivalent of Medicaid in other states. Insurance was collected as a proxy for family socioeconomic status (reference). Leukemia was the most common diagnosis followed by brain tumors, bone tumors and neuroblastoma. A variety of other tumor types were represented; adrenocortical carcinoma, colorectal cancer, ganglioneuroblastoma, hepatocellular carcinoma, nasal sarcoma, mast cell sarcoma, and Wilm's tumor. Children were in all phases of cancer treatment from newly diagnosed to end of life. Nearly half (45%) of the sample was in remission at the time of study. Sixteen percent of the sample consisted of children who were newly diagnosed (last 30 days). The remainders of children (39%) consisted of those with relapsed disease, had residual or progressive disease, were receiving palliative care, or at end of life. Most children were receiving chemotherapy (86.8%) as their main form of disease treatment. Day's since diagnosis and completion of the questionnaire ranged between 4 and 5014, with an average of 488 days and a median of 144 days. Table 2 summarizes the characteristics of the 106 individual children represented in the sample and the 120 child-related observations used for the analysis.

Table 2

Demographic Characteristics – Child with Cancer (Individual and Observations)

Characteristic	Individual		Observations	
	<i>n</i>	%	<i>n</i>	%
Size of group, N	106		120	
Age, mean (range), years, SD	8 (0-20), 5.2		7.9 (0-20)	
Gender ^a				
Male	57	53.8	67	55.8
Female	48	45.3	52	43.3
Health Insurance				
California Children's Services	8	7.5	8	6.7
HMO	18	17	20	16.7
PPO	24	22.6	30	25
Kaiser	1	0.9	1	0.8
Medi-Cal	45	42.5	50	41.7
Military	5	4.7	6	5
Other	5	4.7	5	4.2
Cancer Diagnosis				
Leukemia	55	52	62	51
Lymphoma	5	4.7	7	5.8
Brain or neural tumor	19	17.9	20	16.7
Osteosarcoma/Ewing's sarcoma/Rhabdomyosarcoma	9	8.5	10	8.3
Neuroblastoma	7	6.6	8	6.7
Other	11	10.4	13	10.8
Disease Status				
New diagnosis (within last 30 days)	17	16	19	15.8
Remission	48	45.3	56	46.7
Initial Relapse	2	1.9	2	1.7
Subsequent Relapse (beyond initial)	4	3.8	4	3.3
Progressive Disease	14	11.7	14	11.7
End of life	2	2	2	1.7
Other ^b	20	19	23	19.2
Current Disease Treatment				
None	1	0.9	1	0.8
Chemotherapy	92	86.8	106	88.3
Surgery	1	0.9	1	0.8
Hematopoietic stem cell transplant	5	4.7	5	4.2
Experimental therapy	1	0.9	1	0.8
Palliative Care	3	2.8	3	2.5
Other	3	2.8	3	2.5
Days since diagnosis, mean (range), SD	488.42 (4 – 5014), 918		488.42 (4 – 5014), 918	

^a one missing gender from both groups ^b ten children had residual disease after treatment.

Note. Values expressed as *n* (%) unless otherwise noted. Percentage may not add up to 100% due to missing data or rounding.

Aim 2

Examine the relationships between hope, uncertainty, and coping among a sample of parents with children with cancer receiving services at a large, academic pediatric healthcare center in southern California.

Bivariate correlation was conducted to determine significant relationships between study variables and parent/patient characteristics. Several variables did not demonstrate normal distribution; parent age, HHI score, days since diagnosis, and number of dependent children. Spearman's Rho was used to conduct correlations for these variables. Pearson r was used to correlate normally distributed variables; child age in years, uncertainty, and coping; t -tests were used to compare means for interval and categorical variables. ANOVA was used to compare means of outcome variables (hope, uncertainty, and coping) against categorical variables with 3 or more categories (parent relationship to child, parent race, parent education, child health insurance, child cancer diagnosis, child current disease status, and child disease treatment. For those items with significant F distributions, post hoc comparisons were made using a Tukey's Honestly Significant Differences (HSD) test.

Reliability of Scales

The scales used for this study have been previously used by many other investigators to measure these constructs. Cronbach's alpha was calculated for each composite scale score in this population. Overall, reliability for these scales was high: HHI ($\alpha = .87$), PPUS ($\alpha = .90$), and WOC ($\alpha = .92$). This data indicates in this population, the scales were able to detect true variability due to the constructs studied.

The Herth Hope Index (HHI) provides a score that directly measures level of hope. Higher HHI scores indicate higher hope. The Parent Perception of Uncertainty Scale (PPUS) measure consists of four subscales; ambiguity, lack of clarity, lack of information, and unpredictability. Higher PPUS total scores indicated higher parental uncertainty. A significant negative or inverse correlation was found between hope and uncertainty ($r_s = -.512, p = .01$). In this population the lower parents' hope, the higher their uncertainty. Uncertainty accounts for 26.2% of the variability in hope. As the child's days from diagnosis increase (length of illness), hope decreases ($r_s = -.226, p = .016$) and uncertainty increases ($r_s = .237, p = .014$). Coping is statically significantly related to both parent age and number of children. Coping decreases as parents age ($r = -.207, p = .042$). Interestingly, both legal guardians and custodial caregivers tended to be older ($M = 56.5 \pm 16.4$) as compared to mothers ($M = 37.3 \pm 7.8$) and fathers ($M = 41.3 \pm 10.8$). Coping is statistically significantly related to number of dependent children ($r = .282, p = .005$). See Table 3 for comparisons.

Table 3

Relationships between Parent Age, Number of Dependent Children, Days Since Diagnosis, Hope, Uncertainty, and Coping

Characteristic	Hope	Uncertainty	Coping
	r_s	r	r
Parent			
Parent age	-.070	.137	-.207*
Number of dependent children	.103	.157	.282**
Uncertainty	-.512**		.020
Coping	.020	.073	
Child			
Days since diagnosis	-.226*	.237*	-.085

Note. * $p = .05$ ** $p = .01$

Whether or not parents were in a committed relationship was significantly related to their levels of uncertainty and hope. See Table 4. Parents who are single scored lower

in hope than parents who are in a committed relationship. Parents who were single scored higher in uncertainty and coping but lower on hope than those who were in a committed relationship. There was a significant difference in the uncertainty scores for parents who were single ($M=83.25$, $SD = 18.99$) versus those in a committed relationship ($M=73.15$, $SD 17.74$), as well as hope scores for parents who were single ($M=40.00$, $SD=4.12$) versus those parents in a committed relationship ($M=42.76$, $SD = 5.11$).

Table 4

Independent Samples t-test - Relationships between Uncertainty, Hope, Coping and Parent Relationship Status

Variable	Parent Relationship Status	<i>N</i>	<i>M</i>	<i>SD</i>	<i>t</i>	<i>df</i>	<i>p</i>
Uncertainty	Committed Relationship	85	73.15	17.74	.2.260	103	.026*
	Single	20	83.25	18.99			
Hope	Committed Relationship	89	42.76	5.106	2.354	109	.020*
	Single	22	40.00	4.117			
Coping	Committed Relationship	82	82.12	25.815	-1.427	97	.157
	Single	17	92.59	34.870			

Note. $p < .05$

Computed ANOVA determined significant relationships between demographic and study variables. See Table 5. Uncertainty and parent relationship to child ($F=2.842$, $p = .041$), uncertainty and education ($F=2.423$, $p=.041$) and coping and child insurance ($F=3.217$, $p = .006$) were statistically significant. Hope and child's current disease status and coping and child's current disease status approached significance ($F = 2.10$, $p = .058$). Post-hoc comparisons further delineated which groups differed significantly from each other. Mothers and fathers differed significantly in their level of uncertainty from

legal guardian ($p=.039$ and $p = .023$ respectively). These same tests indicated participants with less than a 12th grade education were significantly different from those who had completed some college or trade school in levels of uncertainty ($p = .021$). Post-hoc tests were not computed for coping and child insurance because at least one of the groups contained less than 2 cases.

Table 5

One-way ANOVA – Significant Variables

Variable	Parent Relationship Status	<i>N</i>	<i>M</i>	<i>SD</i>	<i>t</i>	<i>df</i>	<i>p</i>
Uncertainty	Committed Relationship	85	73.15	17.74	.2.260	103	.026*
	Single	20	83.25	18.99			
Hope	Committed Relationship	89	42.76	5.106	2.354	109	.020*
	Single	22	40.00	4.117			
Coping	Committed Relationship	82	82.12	25.815	-1.427	97	.157
	Single	17	92.59	34.870			

Note. * $p < .05$

Aim 3

Aim 3. Examine the influence of days since cancer diagnosis, parent relationship status, parent relationship to child, parent education, child disease status, hope, and uncertainty on coping.

The results of simultaneous multiple regression analyses influencing the variance of coping in parents of children with cancer are shown in Table 6. Variables for the model were chosen based on demonstrated significance in bivariate analyses (refer to aim 2). The Durbin-Watson statistic indicates observations are independent (2.038). VIF and

tolerance levels confirmed multicollinearity is not a problem. Potential predictors explained 19.3% of the variance in coping ($R^2 = .193$, $p = .011$). Initial relapse negatively predicts coping ($B = -.203$, $t = -2.052$, $p = .043$) while number of dependent children positively predicts coping ($B = .211$, $t = 2.178$, $p = .032$). These are the only significant predictors in this model with initial relapse being the largest contributor to the model.

Table 6

Coping Regression

Variable	B	SE	β	t	p
Parent education: 12 th grade highest	-11.338	6.918	-.160	-1.639	.105
Child disease status: initial relapse	-43.745	21.317	-.203	-2.052	.043
Number of dependent children	4.441	2.039	.211	2.178	.032

Note. Overall $R^2 = .193$, Adjusted $R^2 = .121$, $F(8, 90) = 2.689$, $p = .011$

Supplemental Analyses

Supplemental analyses were conducted to answer the following questions:

Research Question: What is the influence of days since diagnosis, parent relationship status, parent relationship to child, parent education, child disease status, uncertainty, and coping on hope?

The results of simultaneous multiple regression analyses predicting hope in parents of children with cancer are shown in Table 7. Predictors for the model were chosen based on demonstrated significance in bivariate analyses. The Durbin-Watson statistic indicates that observations are independent (2.208). VIF and tolerance levels confirmed multicollinearity is not a problem. Potential predictors explained 19.3% of the variance in hope ($R^2 = .369$, $p = .000$). The only predictor making a significant

contribution to the model is uncertainty ($t(74) = -4.717, p = .000$). As uncertainty increases by one unit, hope decreases by .137 units if all other variables are held constant. All other predictors in the model do not make a significant contribution to this model.

Table 7

Hope Regression

Variable	B	SE	β	t	p
Days since cancer diagnosis	.000	.001	.012	.114	.910
Parent relationship status	-1.629	1.302	-.130	-1.251	.215
Parent relationship to child: Mother	-.163	1.302	-.015	-.138	.890
Parent education – Highest 12 th grade	-.110	1.385	-.009	-.079	.937
Child's disease status – initial relapse	-2.839	3.836	.040	.399	.691
Uncertainty score	-.137	.029	-.495	-4.717	.000
Coping score	-.006	.019	-.035	-.337	.737

Note. Overall $R^2 = .369$, Adjusted $R^2 = .250$, $F(14, 74) = 3.096$, $p = .001$

What is the influence of days since diagnosis, parent relationship status, parent relationship to child, parent education, child disease status, hope, and coping on uncertainty?

The results of simultaneous multiple regression analyses predicting uncertainty in parents of children with cancer are shown in Table 8. Predictors for the model were chosen based on demonstrated significance in bivariate analyses. The Durbin-Watson statistic indicates observations are independent (2.327). VIF and tolerance levels confirmed multicollinearity is not a problem. Potential predictors explained 41% of the variance in uncertainty ($R^2 = .405, p = .000$). The only predictor making a significant contribution to the model is hope ($t(74) = -4.717, p = .000$). As uncertainty increases by one unit, hope decreases by 1.693 if all other variables are held constant. All other predictors in the model do not make a significant contribution to this model.

Table 8

Uncertainty Regression

Variable	B	SE	β	<i>t</i>	<i>p</i>
Days since cancer diagnosis	.002	.002	.115	1.117	.268
Parent relationship status	.838	4.632	.018	.181	.857
Parent relationship to child: Mother	2.321	4.141	.058	.560	.577
Parent education – Highest 12 th grade	-5.161	4.841	-.111	-1.066	.290
Child's disease status – initial relapse	11.773	13.485	.083	.873	.385
Hope score	-1.693	.359	-.467	-4.717	.000
Coping score	.049	.066	.075	.743	.460

Note. Overall $R^2 = .405$, Adjusted $R^2 = .293$, $F(14, 74) = 3.601$, $p = .000$

Summary

This analysis provides interesting and compelling data about relationships between hope, uncertainty, and coping in a group of parents whose child is being treated for cancer. Significant correlations were used to build regression models to evaluate the contribution of each variable included. The meaning of this data and its usefulness to clinical practice will be discussed in Chapter 5.

Chapter 5

Discussion of Findings

The purpose of this cross-sectional, exploratory study was to characterize a sample of parents whose children were being treated for cancer, describe the disease and demographics of the children being treated, and explore relationships between these variables and hope, uncertainty, and coping. Coping was the primary outcome measure. Mishel's Uncertainty in Illness model was used as the conceptual framework to study these phenomena. This framework suggests a stimuli frame that triggers a condition of uncertainty and the need to appraise the situation. This appraisal is affected by cognitive capacities and structure providers. Uncertainty then is appraised as either an opportunity or a threat that employs buffering, mobilizing and affective coping strategies leading to adaptation (Mishel, 1981). In this chapter will study findings, strengths and limitations, and implications for nursing practice, education, policy, and future research are discussed.

Study Summary

Data were collected from 120 parents whose child was being treated for cancer at a single, comprehensive, pediatric cancer center located in southern California. Data was also abstracted from the electronic medical record (EMR) for the child of each parent who consented. Data collection occurred over a 14 month period. Both English-speaking and Spanish-speaking parents participated. Data analysis was conducted using descriptive, inferential, and multivariate measures as appropriate for the research aim.

Study Findings

Parents

Consistent with many other studies of parents of children with cancer, the vast majority of this sample was comprised of mothers (75%) (Grootenhuis & Last, 1997; Norberg et al., 2005; Pai et al., 2007). Mothers still assume the majority of child care, especially for a sick child (Sloper, 2000; Svavarsdottir, 2005). While care for both parents needs to be provided, interventions focusing on the bedside caregiver need to recognize mothers most often hold this role.

This parent population was nearly 50% Hispanic. This is reflective of the geographic area in which the hospital resides. While ethnicity did not appear to be significant in the analysis, it does present a more diverse population than most other studies. This study also evaluated parents whose primary language was Spanish. Only one other study in the literature on parents of children with cancer was completed with Spanish-speaking parents in Brazil (Quintana et al., 2013). In contrast the majority of literature on coping in parents conducted outside the United States has been done in the United Kingdom and Scandinavian countries with primarily white families.

This study found as parent age increases, coping decreases. There is nothing in the literature to support or refute these findings. A small subset of the parent group was comprised of legal guardians and custodial caregivers. These caregivers were often grandparents. It's difficult to speculate why this older group experienced decreased coping. Perhaps non-parent caregivers are considered not to be as invested in the child's illness and therefore receive less support.

Insurance was used as a proxy for socioeconomic status. Nearly half of the parent population in this study had obtained Medi-Cal insurance for their child's care. Medi-Cal is only available for low income families. Kylma and Juvakka (2007), found poor parental resources including low income endanger hope. Low income and low savings are significant negative predictors of optimism (Fayed, Klassen, Dix, Klaassen, & Sung, 2011). Although ANOVA indicated child's insurance was significantly correlated to coping in multiple regression analysis, insurance did not contribute significantly to the model.

Parents in this study were fairly well educated. Nearly 40% of parents had obtained a bachelor's degree or higher. Almost 30% had obtained an associate's degree or finished some college or trade school. The remaining 30% had a high school level education or less. Education is a factor in the stimuli frame of Mishel's model. Education appears to be a filter through which parents interpret the severity of their child's disease and treatment. In this study, those with a lower educational level had lower coping scores. This conflicts with Eapen and Revesz (2003) who did not find any correlation between coping and parental education in a cohort of patients from the United Arab Emirates (UAE).

Parents in this study had a mean of 1.7 dependent children other than the child with cancer. Number of dependent children has been evaluated in previous studies but has not been significantly related to any measured outcomes. In this study, number of dependent children was positively correlated with coping. Since this analysis did not evaluate subscales of coping, it's not known whether parental coping was positive in nature (planful problem-solving) or negative (avoidance). Number of dependent children may give future researchers insight into coping mechanisms used by parents.

Most of the participants in this study reported being in a committed relationship (80%). Parents who were single had higher uncertainty scores and lower hope scores than those in a committed relationship. A systematic review of family adjustment to a pediatric cancer diagnosis found single parents experience less support and feel more responsibility for all aspects of cancer care including demands outside the hospital (other family members, employment) (Long & Marsland, 2011).

Child with cancer

Children in this sample represented a wide range of ages, diagnoses, current treatments, and various disease states ranging from newly diagnosed to end of life. The only child-related variables contributing any significance in the analysis were current disease status and days since diagnosis (i.e. length of illness at time of study). Grootenhuis and Last (1997), in their study of predictors of parental adjustment found lack of positive expectation about the course of illness, (e.g. disease relapse), was the strongest predictor of negative emotions in parents of children with cancer. In a study of fathers of children with cancer, length of diagnosis was positively correlated to a confrontive coping style and negatively correlated to uncertainty (Sterken, 1996). In this

sample, the first relapse of a child significantly decreased parental coping. Norberg (2005) found type of coping strategy and level of coping did not differ based on time since diagnosis in parents of children with cancer. De Graves and Aranda (2005) evaluated the reflections of health professionals dealing with parents of children with difficult to treat cancer. They found relapse was a very significant and difficult turning point in a child's illness which increased parental uncertainty. When a child relapses, initial expectations for cure are altered and uncertainty increases (De Graves & Aranda, 2005; Jennifer W Mack & Wolfe, 2006).

Coping

The effect of different variables on coping was explored using bivariate analysis and multivariate linear regression. Parent age, number of dependent children and insurance were all significant in bivariate analysis, however when included in a regression model, only child disease status and number of dependent children explained the variability in coping.

Hope and uncertainty were not correlated with coping and neither contributed to the model for coping. De Graves and Aranda (2008) found families struggling with uncertainty during the time of relapse, fluctuated between fear and hope. These families did not achieve adaptation as described by Mishel (1988). The literature often discusses the role of hope in coping, but hard data is sparse. Both Folkman (2010) and Lazarus (1999), creators of the Ways of Coping Questionnaire used in this study have postulated coping is the result of an appraisal. The appraisal determines the means by which we "think, feel, and act to advance our cause" (Lazarus, 1999, p. 658). Folkman suggests when odds are unfavorable in an illness, a reappraisal takes place. This reappraisal is

personalized which gives hope a “toehold within the individual’s psychological milieu” (Folkman, 2010, p. 903). A person’s ability to cope with adverse situations depends on having at least some hope in regard to their outcome. They view coping as an adaptive behavior stimulated and sustained by hope. Groopman (2004) supposed to have hope was to have a belief in the ability to have some control over one’s circumstances. In a meta-analysis of the ontology and epistemology of hope, hope was found to be a dynamic process and a necessary condition for activity (i.e. coping) (Kylma & Vehvilainen-Julkunen, 1997). In a study of families of children with leukemia, parental hope as well as social and family communication was the most important factor helping the child to cope with the disease, however, it was not directly associated with parental coping (Eapen, Mabrouk, & Bin-Othman, 2008).

It is often parents, themselves, who propose hope is essential to their ability to cope. Parents of children receiving palliative care for a brain tumor identified maintaining hope as a key coping mechanism. Knapp and Komatz (2011), in evaluating preferences for end of life care, found parents were willing to allow their child to experience a poor quality of life and shortened survival with chemotherapy if it meant being able to hold on to hope. This was considered an important factor in decision-making which has been considered a function of coping (Stewart et al., 2012). Parents whose child had a poor prognosis found hope to be critical to upholding morale and continued functioning (Barrera et al., 2013). Bland and Darlington (2002) studied caregivers of people with serious mental illness and found families most often voiced the need for hope in order to cope with their loved one’s disease.

Two studies have quantitatively measured the effect of hope on coping among parental caregivers. One study measured hope, uncertainty, and adaptation in caregivers of children with Down syndrome (Truitt et al., 2012). In the current study, hope and uncertainty were significant independent predictors of adaptation accounting for 13% of the variance in adaptation. This study used different measures for both hope and coping (i.e. adaptation). In a study by Lin, Yeh, and Mishel (2010) lower parental uncertainty was associated with more coping. Lin, Yeh, and Mishel's study (2010) was the only study on parents of children demonstrating a relationship between lower uncertainty and higher coping.

While coping has been considered an important outcome of hope in much of the literature, these assertions were not supported by this study. Conceivably, hope (or the condition necessitating hope) is a trigger for coping but may not directly influence levels of coping. Many have stated that coping is a highly individual process, dependent on the circumstances surrounding the thing or situation 'hoped for'. Perhaps coping in the context of this study was not appropriately characterized by the chosen measure.

Hope

The effect of different variables on hope was explored using bivariate analysis and multivariate linear regression. Uncertainty, days since diagnosis, and parent relationship status were all significant in bivariate analysis, however when included in a regression model, only uncertainty explained the variability in hope.

In this model, uncertainty accounted for 37% of the variance in hope. Uncertainty sets the stage for hope, especially in light of a potentially life-threatening illness. Hope has been found to be both tenacious and tenuous, yet ever present, based on levels of

uncertainty (Barrera et al., 2013). Parents described themselves as “bearers of hope”, maintaining hope despite a poor prognosis. Relapse and disease progression lead to increased uncertainty, yet parents hold out hope for a cure. Kars and Grypdonck (2011) found all parents took certainty (or the lack of it) into consideration when considering whether to allow their child with cancer die. Most parents actively maintained uncertainty. Hope is a modulator for uncertainty. It allows parents the opportunity to delay confronting loss while transitioning from a ‘preserving’ to a ‘letting go’ perspective (Heinze & Nolan, 2012).

Uncertainty

The effect of different variables on uncertainty was explored using bivariate analysis and multivariate linear regression. Hope, days since diagnosis, parent relationship status, parent relationship to child, parent education, child disease status, and coping were all significant in bivariate analysis, however when included in a regression model, only hope explained the variability in uncertainty. The literature does not offer much on the relationship between uncertainty and hope (except as described above). Relapse and disease progression are characterized by increasing uncertainty (De Graves & Aranda, 2005). Hoven and colleagues (Hoven et al., 2008) found that a child’s complicated cancer was associated with more parental uncertainty and distress. Granek, Barrera, Shaheed, et al. (2013) evaluated the trajectory of hope when a child has ‘difficult to treat’ cancer. Their qualitative study found that as the child’s condition deteriorated over time, hope for a miracle increased, while hope for a future decreased. Mothers of pediatric cancer patients also reported as time progressed, uncertainty and maternal

distress increased (Liu & Yeh, 2010). Bally (2013) found parents fear the loss of hope as the disease progresses and want to ‘keep hope possible’.

Conceptual Framework

Mishel’s middle range Theory of Uncertainty in Illness was used as the conceptual framework for this study. Middle range theories attempt to explain specific phenomena (e.g. uncertainty) and are appropriate for empirical testing. Findings from this study will be linked to pertinent elements of the conceptual framework proposed by Mishel (1988).

Stimuli Frame

The stimuli frame consists of those stimuli an individual receives and uses to form a cognitive schema for illness-related events. The stimuli components are 1) symptom pattern, 2) event familiarity, 3) and event congruence. The stimuli frame is influenced by cognitive capacity and structure providers.

Disease status and time since diagnosis are the main stimuli affecting symptom pattern and event familiarity. In this study only initial relapse was significantly related to the outcome of coping. Disease status is also related to event familiarity as parents whose children relapse recognize familiar symptoms of the returning disease. Time since diagnosis was correlated with hope and uncertainty. Children who have been in treatment longer have parents who are veterans within the system. While familiar with treatments and the hospital environment, the long-term nature of the disease led parents in this study to experience increased uncertainty and decreased hope as length of disease increased.

Structure Providers

Education serves as a structure provider. In this study, parents with less than a 12th grade education experienced more uncertainty than parents with more education. Parents with low educational level may lack understanding and knowledge needed to navigate the health care system and make complex decisions (Mishel, 1983). Another structure provider identified in this study is relationship status. Parents who were in a committed relationship experiences less uncertainty and more coping. The ability to discuss and clarify issues with support from others aids in forming a cognitive schema through which to interpret meaning (M. Mishel, 1988). Parent relationship to child might also be considered a structure provider. In this study, both mothers and fathers differed significantly from legal guardians and custodial caregivers in their level of uncertainty. Actual parents had less uncertainty than legal guardians and custodial caregivers. Perhaps the fiduciary responsibility of these caregivers compounds their level of uncertainty.

Appraisal of Uncertainty

The appraisal of uncertainty was certainly affected by several factors. Parent relationship to child, education level of parent, and days since diagnosis (i.e. length of illness) were all correlated with uncertainty. What's interesting in this study is that hope was highly correlated with uncertainty. As hope increased, uncertainty decreased and vice versa. In Mishel's model, hope is the result of an appraisal, it does not figure into the pre-appraisal stimuli frame or the structure providers. This data would suggest a more interactive or cyclical pattern of hope and uncertainty where one begets the other.

Coping and Adaptation

While this study did not evaluate adaptation, it did measure levels of coping. The largest variance in coping in this study was explained by parent education, disease status (specifically initial relapse), and number of dependent children. Hope and uncertainty were not significant in the statistical model for this sample. This is a vast deviation from Mishel's model which suggests that the appraisal of uncertainty leads to either opportunity (hope) or danger and coping and adaptation flow out of that appraisal.

Limitations

There are several limitations to the current study. This was a cross-sectional, descriptive design with 120 parents of children with cancer at a single institution. The participants were chosen by convenience. The findings from this non-random sampling procedure should not be interpreted as establishing any cause and effect relationships. Parent data was collected using self-report measures. The use of self-report measures is subject to concerns for validity and accuracy (Denise F. Polit & Beck, 2011). Measures chosen to evaluate the variables under study; hope, uncertainty, and coping while valid and reliable in previous studies may not have been appropriate for this parent population. This was a very diverse sample with nearly 50% of participants being Hispanic/Latino. Although these scales were translated into Spanish, the concepts could have different meanings due to cultural influences. However, diversity could also be viewed as a strength of the study. Most studies on these concepts have been conducted in primarily white populations. Participants were recruited primarily from the inpatient unit and the outpatient treatment room in which patients receive supportive therapies (blood, chemotherapy, fluids, etc.). Parents and patients who were considered "fragile" and at

risk for emotional distress were not approached which certainly influenced the type of parent recruited and thus the findings of this study. Despite these limitations findings from this study provide important data on the important role hope, uncertainty, and coping as well as key demographic factors play in the experience of parents caring for their child with cancer.

Implications

Nursing Practice

Nurses are profoundly affected by the families and patients they care for. As primary, frontline caregivers, nurses are often interpreters of information and serve as the sounding board for frustrations and grief (Beckstrand et al., 2009). Families rely on nurses to provide information and interpret medical jargon. Nurses need to communicate clearly, compassionately, and collaboratively with families (Feudtner, 2007) .

Understanding factors that affect hope, uncertainty, and coping among parents may allow nurses more insight into the complex emotions of parents as they parent their child with cancer. This study suggests nurses need to be aware of parent factors that affect their level of uncertainty and their ability to maintain hope. Parents with a lower educational level, custodial caregivers, and single parents may require more teaching, explanation, and time to acquire information and understanding. Parents of low income and those with a higher number of dependent children may require additional psychosocial support to navigate the struggles associated with the diagnosis. Nurses also need to be aware that as disease status changes and time from diagnosis increases, parents are more at risk for decreased hope and increased uncertainty. Providing information in a thoughtful and sensitive way is of critical importance. The information in this study could also benefit

members of the interdisciplinary team including physicians, social workers, psychologists, and child life specialists.

Education

Nurses who work with children and families with cancer require special training about communication and psychosocial considerations. End of Life Nursing Education Consortium (ELNEC) has been training nurses in end of life care for the past nine years (“American Association of Colleges of Nursing,” n.d.). This curriculum focuses on psychosocial issues, communication, self-care, and physical nursing care for dying pediatric patient. The concepts learned in ELNEC would provide nurses with tools for interacting with all cancer patients and their families regardless of disease status. Nurses who attend ELNEC can come back to their institutions and share the information with others.

Pre-licensure nurses also need education in the issues surrounding care for the pediatric cancer patient and their family. While the focus is on safe care, students should be aware of the psychosocial dynamics that occur in families caring for a child with cancer. Their communication practices should be tailored to the needs of the family and the child. Insight into hope, uncertainty, and coping may allow the student to better empathize with families.

Policy

Cancer in a child begins a crisis for the family. Parents whose children are diagnosed with cancer need psychosocial support services from diagnosis to completion of treatment to successfully navigate this experience. The Institute of Medicine recommends that families of children with cancer have abundant access to case

management, disease management, discharge planning, and home-based care services to help provide continuity of care (Field & Behrman, 2003). Given that most children with cancer survive their disease, long term follow-up must be considered. As more and more children move into survivorship, psychosocial late effects and their impact on patients and families must be addressed and treated (American Academy of Pediatrics, 2009).

The American Academy of Pediatrics recommends that children with cancer and their families have access to specially trained pediatric oncology nurses, physicians, social workers, psychologists, child life specialists, and access to family support services (American Academy of Pediatrics, 2004). Recent changes in healthcare legislation are ensuring access to care for many more individuals including children. Healthcare providers need to work with policymakers to ensure psychosocial services remain available and robust for patients and families. Nursing organizations, such as the Association for Pediatric Hematology/Oncology Nurses (APHON) need to be actively involved in health policy, advocacy, and disseminating information about those activities to its constituents.

Research

Few studies have quantitatively evaluated hope, uncertainty, and coping among parents of pediatric cancer patients. This study suggests the concepts of hope and uncertainty are closely connected. Although coping was thought to be an important outcome for the parents in this study, the data did not endorse this supposition. Coping is a complex and highly personalized construct that may not lend itself to standardized measurement or perhaps the measure was not specific enough to the coping of a parent of

a child with cancer. While qualitative assessments have shown the value of coping, the quantitative evidence for coping as an outcome requires more investigation.

This study also found single parents, older caregivers, and parents with less than a 12th grade education experienced more uncertainty. As family constellations continue to enlarge beyond the traditional 2-parent family, alternative family roles should be included in future research about caregivers. This study also supports the need to continue to evaluate the impact of support systems (both familial and institutional) on family function. The increasing number of days since diagnosis (i.e. length of disease) was also tied to higher levels of uncertainty. As parents and children enter the post-treatment phase and beyond, additional study should be done on hope, uncertainty, and coping as the literature suggests uncertainty does not dissipate with time (Roberta Lynn Woodgate & Degner, 2002).

Conclusion

Hope, uncertainty, and coping are important constructs in the milieu of parents of pediatric cancer patients. Parents of children with cancer have the daunting task of both parenting and caring for their ill child while maintaining family function. Pediatric nurses are partners in care with families. They are at the bedside day in and day out.

Understanding the factors that affect these families provides both insight and information needed for nurses to provide relevant, sensitive care that promotes not only physical health but emotional well-being. This study indicates hope, uncertainty, and coping, as well as key demographic factors play an important role in the experience of parents caring for their child with cancer.

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Appendix A



ENTERED
3/12/15

Institutional Review Board Project Action Summary

Action Date: March 12, 2015

Note: Approval expires one year after this date.

Type: ☐ New Full Review ☐ New Expedited Review ☐ Continuation Review ☒ Exempt Review
☐ Modification

Action: ☒ Approved ☐ Approved Pending Modification ☐ Not Approved

Project Number: 2015-03-186

Researcher(s): Christine Sloan Doc SON
Dr. Cynthia Connelly Fac SON

Project Title: Hope, Uncertainty and Coping among Parents of Children with Cancer

Note: We send IRB correspondence regarding student research to the faculty advisor, who bears the ultimate responsibility for the conduct of the research. We request that the faculty advisor share this correspondence with the student researcher.

Modifications Required or Reasons for Non-Approval

None

The next deadline for submitting project proposals to the Provost's Office for full review is N/A. You may submit a project proposal for expedited review at any time.

Dr. Thomas R. Herrinton
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Appendix B

Hope, Uncertainty and Coping in Parents of Children with Cancer CHILD Data Extraction Form

Today's Date: ____ (mo)/ ____ (day)/ ____ (yr)

1. Age (in years & months): ____ (years)/ ____ (months)
2. Gender: ☐ Female
 ☐ Male
3. Health Insurance:
 - ☐ California Children's Services (CCS)
 - ☐ Insurance: HMO
 - ☐ Insurance: PPO
 - ☐ Kaiser
 - ☐ Medi-Cal
 - ☐ Military
 - ☐ None/Self-Pay
 - ☐ Other: _____
4. Cancer Diagnosis:
 - ☐ Leukemia
 - ☐ Lymphoma
 - ☐ Brain or Neural Tumor
 - ☐ Sarcoma (Osteosarcoma, Ewing's, rhabdomyosarcoma)
 - ☐ Neuroblastoma
 - ☐ Other – please specify _____
5. Date of initial cancer diagnosis: ____ (mo)/ ____ (day)/ ____ (yr)
6. Current Disease Status:
 - ☐ New diagnosis (within last 30 days)
 - ☐ Remission
 - ☐ Initial Relapse
 - ☐ Subsequent Relapse
 - Number of relapses including the current one _____
 - ☐ Progressive disease
 - ☐ End of Life - Allow Natural Death (AND) order in place
 - ☐ Other: _____
7. Current Disease Treatment
 - ☐ None
 - ☐ Chemotherapy
 - ☐ Radiation
 - ☐ Surgery
 - ☐ Bone Marrow/Stem Cell Transplant
 - ☐ Experimental Therapy
 - ☐ Palliative Care
 - ☐ Other: _____

Appendix C

Hope, Uncertainty and Coping in Parents of Children with Cancer Parent Questionnaire

Please answer the following information about YOU as the parent or guardian.

Today's Date: ____ (mo) / ____ (day) / ____ (yr)

Your age (in years): _____

1. Your gender: ☐ Female
☐ Male
2. Your personal relationship status (check one):
☐ In a committed relationship
☐ Single
3. Your relationship to the child who is being treated at the Peckham Center at Rady's:
☐ Mother
☐ Father
☐ Stepmother
☐ Stepfather
☐ Other : (specify) _____
☐ Legal Guardian: (specify) _____
4. Your ethnicity:
☐ Hispanic/Latino
☐ Non-Hispanic/Latino
5. Your race:
☐ American Indian/Alaska Native
☐ Asian
☐ Black or African American
☐ Native Hawaiian/Other Pacific Islander
☐ White/Caucasian
☐ Other – please specify _____
6. Mark the highest level of education you have completed:
☐ Less than 12th grade
☐ High School or GED
☐ Some college or trade school
☐ Associates Degree (2 year)
☐ Bachelors of Science or Arts (4 year)
☐ Graduate or doctoral degree
7. Number of dependent children NOT including the child who is being treated at the Peckham Center:
☐ 0
☐ 1
☐ 2
☐ 3
☐ 4 or greater: _____

Appendix D



Christine Sloan <csloan100@pointloma.edu>

RE: Hope Herth Index Question

1 message

Herth, Kaye A <kaye.herth@mnsu.edu>
To: Christine Sloan <ChristineSloan@pointloma.edu>

Wed, Feb 13, 2013 at 12:54 PM

Dear Christine,

I am excited about your interest in hope, uncertainty and coping among parents of children with high risk cancer. I believe that the Herth Hope Index (HHI) is very appropriate for use with parents of children with cancer and have attached several reference lists on hope that may be of help to you. I have also attached a copy of the HHI, the longer Herth Hope Scale (HHS), and scoring instructions.

You have my permission to use either the HHI or the HHS in your research project. If you decide to use either tool, I would appreciate receiving a summary of your findings upon completion of your study.

Best wishes on your educational journey and important research study. If I can be of any further assistance please don't hesitate to contact me.

Sincerely,

Dr. Kaye Herth

Kaye A. Herth, Ph.D., R.N., F.A.A.N.
Minnesota State University, Mankato
Dean Emerita
kaye.herth@mnsu.edu <<mailto:kaye.herth@mnsu.edu>>

From: Christine Sloan [ChristineSloan@pointloma.edu]
Sent: Tuesday, February 12, 2013 2:31 PM
To: Herth, Kaye A
Subject: Hope Herth Index Question

Hello Dr. Herth,

I am currently a doctoral student at the University of San Diego, Hahn School of Nursing. I am conducting a descriptive research study on Hope, Uncertainty and Coping Among Parents of Children with High Risk Cancer. I see that you have used it with family members but I am assuming that this was in regard to adult patients. I like your scale better than Snyder's Hope Scale because it has a broader conceptual basis.

What are your thoughts about the appropriateness of using the HHI in parents whose children have cancer? If you think it appropriate, how do I obtain your permission to use the scale? Thank you!!

Study No.

HERTH HOPE INDEX

Listed below are a number of statements. Read each statement and place an [X] in the box that describes how much you agree with that statement right now.

	Strongly Disagree	Disagree	Agree	Strongly Agree
1. I have a positive outlook toward life.				
2. I have short and/or long range goals.				
3. I feel all alone.				
4. I can see possibilities in the midst of difficulties.				
5. I have a faith that gives me comfort.				
6. I feel scared about my future.				
7. I can recall happy/joyful times.				
8. I have deep inner strength.				
9. I am able to give and receive caring/love.				
10. I have a sense of direction.				
11. I believe that each day has potential.				
12. I feel my life has value and worth.				

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1999 items 2 & 4 reworded

Appendix E

Request Form: PPUS

I request permission to copy the Parents' Perception in Uncertainty Scale for use in my research entitled:

Hope, Uncertainty & Coping among Parents
of Children with High Risk Cancer

In exchange for this permission, I agree to submit to Dr. Mishel, upon completion of the study, a printout of the uncertainty data and an electronic submission or CD containing the data with the data dictionary. The data must contain information on each subject's age, sex, education, and diagnosis, along with data on each subject's response to each item on the scale. This data will be used to establish a normative database for clinical populations. No other use will be made of the data submitted. Credit will be given to me in reports of normative statistics that make use of the data I submitted for pooled analyses. Credit will be given to me in any reports referring to my findings.

Christine Sloan
(signature)

1/30/13
(date)

Positions and full address of Investigator

Christine Sloan RN, MSN, CNS
Assistant Professor, School of Nurs.
Point Loma Nazarene University
3900 Lomaland Dr., San Diego, CA

EMAIL:

christinesloan@pointloma.edu 92106

Permission is hereby granted to copy the PPUS for use in the research described above.

Merle Mishel
Merle H. Mishel

2/6/13
Date

Please send two signed copies of this form to: Merle H. Mishel, PhD, FAAN; School of Nursing, CB #7460 Carrington Hall, University of North Carolina, Chapel Hill, NC 27599-7460

Appendix F

For use by Christine Sloan only. Received from Mind Garden, Inc. on May 3, 2013



www.mindgarden.com

To whom it may concern,

This letter is to grant permission for the above named person to use the following copyright material for his/her thesis or dissertation research:

Instrument: *Ways of Coping Questionnaire*

Authors: *Susan Folkman, Ph.D. and Richard S. Lazarus, Ph.D.*

Copyright: *1988 by Consulting Psychologists Press, Inc.*

Five sample items from this instrument may be reproduced for inclusion in a proposal, thesis, or dissertation.

The entire instrument may not be included or reproduced at any time in any other published material.

Sincerely,

A handwritten signature in black ink, appearing to read "Robert Most", with a long horizontal line extending to the right.

Robert Most
Mind Garden, Inc.
www.mindgarden.com